

TOWARDS SELF-FORGIVENESS
AND SELF-WORTH:
JOURNEYS OF BIRTH MOTHERS OF
CHILDREN WITH FASD

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ABSTRACT

The purpose of this study was to come to a greater understanding of the experiences of birth mothers of children with FASD since the birth of their child. The principles of feminist research practice were utilized throughout in order to give a voice to the women who participated in the study. The research followed the general guidelines to conducting hermeneutic phenomenology outlined by van Manen (1990). Purposeful sampling was used to recruit four birth mothers of children with FASD who have been involved in the mothering of that child. Data was generated through three semi-structured interviews with each participant, including a hermeneutic interview in which the women participated in the process of interpretation. Data was analysed using selective, detailed and wholistic methods and through the process of writing and re-writing (van Manen, 1990).

The results focus on the social and emotional experiences of the women who participated in the study. The experience of being a birth mother of a child with FASD is represented in a discussion of four main themes: Living with the Past: Self-Forgiven, yet Always Present; Living with Others: Judgement and Understanding; Living with the Self: Unworthy and Unfit; and Living with Ambivalence: Mothering as a Birth Mother. The implications of this research in relation to the understanding of the experiences of birth mothers of children with FASD and potential supports are discussed.

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FORWARD

Bracketing, or epoché, is a phenomenological concept in which the researcher lays aside their own presuppositions regarding a phenomenon in order to come to a new understanding of the essence of a phenomenon (Langdrige, 2007). Although I do not personally believe that any individual can observe a phenomenon or carry out research without the influence of their own biases and beliefs, I do believe in the importance of attempting to keep one's own biases and assumptions aside as much as possible throughout the research process. It is with that in mind that I will acknowledge my own assumptions regarding the phenomenon in question. In order to fully explain these assumptions, I will give a bit of a background on how I came to arrive at this research topic.

My interest in this area has developed over two years of work experience with the FASD Support Network of Saskatchewan, where I was both a Mentor-Advocate and an Employment Support Coordinator for adults with Fetal Alcohol Spectrum Disorder (FASD). In working closely with individuals with FASD, I became involved in many aspects of their lives, and often looked to their families for support. I developed close working relationships with many of the mothers of the individuals I worked with, and was often struck by the depth of emotion displayed by birth mothers when discussing their role in their child's disability. At the beginning of this Master's program, when deciding what topic to focus on for my thesis, I decided that the birth mothers of children with FASD would be a group of individuals who could teach a great deal about the phenomenon of FASD, as well as about the needs of their children and other women like themselves. I thought of several women whom I had worked with over the past few years as I engaged in this decision making process, and thought of the many lessons they had taught me and the wealth of information and experiences they could share.

After deciding that birth mothers of children with FASD would be an important population to learn from, I had a discussion with a former co-worker about the possible research ideas. She shared a quotation which a birth mother in British Columbia had written in a recent article. The woman had stated that she feels like she does not have the right to ask for help because she caused the harm to her child. Looking up the article, I later found the exact quotation "You don't even know if you have the right to ask for help because you've done this to your child—not on purpose, but I caused this," (Folland, cited in Lawrence, 2008). The article later went on to discuss the stigma and fear related to being the birth mother of a child with FASD, "It became

something hush-hush and something fearful. I worried that I could have my daughter taken away from me because of it...There's still that stigma around it that they think you're a raging alcoholic that purposely wanted to cause your child damage. It's ludicrous." (Folland, cited in Lawrence, 2008).

The possible implications of these issues for both birth mothers and their children seemed vast to me. How many mothers are out there struggling to raise their child, afraid to ask for help? How many children could benefit from extra support, but are unable to access it? What impact do these feelings have on the mother-child relationship? I began to think back to conversations with other mothers, and the guilt they had expressed over the events in their pregnancies. Thinking back to my experiences working at the FASD Support Network, I also remembered the reactions that people had when I told them where I worked. "How can people still do that to their children?" or "Those mothers should be locked away" were common reactions. Blame of the mother seemed to come from both external and internal sources.

I then began the process of research for this thesis, with these experiences and opinions in mind. My major assumption in beginning this research was that I believe that guilt plays a large role in the lives of many birth mothers of children with FASD, and that community members are also quick to place blame on these mothers, thus increasing feelings of responsibility and self-blame. I began this research with a curiosity about whether these experiences are common, and about the experience of being a birth mother of a child with FASD.

CHAPTER 1

INTRODUCTION

The term Fetal Alcohol Spectrum Disorder (FASD) is used to describe a range of disabilities caused by prenatal exposure to alcohol. Children with FASD face a variety of difficulties, some associated with learning and attention problems; others related to behaviour or executive functioning deficits. The term FASD is not a diagnosis in itself; it is an umbrella term used to describe the range of disabilities caused by prenatal exposure to alcohol (Chudley et al., 2005). It is estimated that 9 babies in every 1,000 born in Canada have FASD (Public Health Agency of Canada, 2003). Throughout this document, I will use the term FASD to refer to individuals with any of the diagnoses under the spectrum of prenatal exposure to alcohol. If specific diagnostic terms such as Fetal Alcohol Syndrome (FAS) are used in the discussion of previous research, I am using that term to describe the exact population that was involved in the study.

The majority of the research in the area of FASD has focused on those affected by FASD; their disabilities, characteristics, and the etiology of the disability. Birth mothers of children with FASD are a group of individuals on which there is limited information available. The research that is available has been prevention-focused, seeking to discover a group of risk factors that may indicate a woman may give birth to a child with FASD (Astley, Bailey, Talbot, & Clarren, 2000a, 2000b). These studies have shown that birth mothers of children with FASD often come from the most impoverished and marginalized groups in society (Astley et al., 2000a; 2000b; May et al., 2005; May et al., 2008).

All but one of the diagnoses under the spectrum of FASD requires confirmation of maternal drinking during pregnancy. These diagnoses thus blame the mother for the cause of the child's disability and for the creation of a "social problem" (Armstrong, 2003, p. 105). The media attention in Canada has been largely blaming, and public opinion often advocates for punitive measures against women who abuse alcohol during pregnancy (Eliason & Skinstad, 1995; Rutman, Callahan, Lundquist, Jackson & Field, 2000; Szabo, 2000). Although Canadian women are not subjected to criminal charges for drinking during pregnancy, women are often punished by the removal of their children by child protection services (Boyd, 2007b).

This public stigma faced by women who give birth to children with FASD has been echoed in the words of the women themselves. Birth mothers of children with FASD have been found to feel guilt and shame in relation to their child's disability (Badry, 2008; Healthy Generations,

2008; J. Salmon, 2008). Feelings of guilt and shame related to one's actions may be destructive and may be linked to depressive symptoms and psychopathologies (Dost & Yagmurlu, 2008). It has also been found that in cases where an individual feels guilt for an action they are unable to repair, they may engage in forms of self-punishment (Nelissen & Zeelenberg, 2009).

This blaming attitude from the Canadian public, combined with the sentiments of many birth mothers related to guilt and stigma, led me to question the nature of the experience of being a birth mother of a child with FASD. One study has examined the experiences of birth mothers after the birth of their child in New Zealand (J. Salmon, 2008), and another examined birth mothers' experiences in Alberta, with a focus on their journey's before becoming a birth mother (Badry, 2008). However, there is limited information on women's experiences of being a birth mother in Canada since the time of pregnancy. Furthermore, in light of the recent literature illuminating the Canadian blaming attitude towards birth mothers of children with FASD (Armstrong, 2003; Boyd, 2007; Marcellus, 2007), more information is needed on how stigma affects the lives of birth mothers of children with FASD. A greater understanding of these women's experiences could assist in the building of positive and non-judgemental support.

In order to better understand the experiences of birth mothers of children with FASD, I questioned: what is the essence of the experience of birth mothers of children with FASD since the birth of their child? I engaged in a hermeneutic phenomenological study, drawing largely on the works of Max van Manen (1990). Hermeneutic phenomenology attempts to describe and interpret the essence of a human experience (Langdridge, 2007). In using this methodology, I attempted to come to a better understanding of the essence of the experience of being a birth mother of a child with FASD. In-depth interviews were conducted with four women in Saskatchewan who are birth mothers of a child with FASD and who are currently parenting that child. I interviewed each woman three times, in order to develop rapport, maintain a respectful research relationship, and engage in collaborative data generation. The interviews were transcribed and the data were analysed according to the methods outlined by van Manen (1990).

In order to remain respectful and to truly value the voices of the women involved in the study, I employed a feminist standpoint (Hesse-Biber & Leavy, 2007) throughout this research. In doing so I hoped to give voice to women who have been historically oppressed and marginalized; value personal and emotional information; and pay careful attention to social and political contexts when evaluating information. In using a feminist standpoint I sought to

understand the world through the eyes of oppressed women and apply that knowledge to social activism (Hesse-Biber & Leavy, 2007). Thus I did not enter into this research as a value-free researcher, but rather I sought to be reflexive throughout, acknowledging my own role in the research process.

The women taught me a great deal about the experience of being a birth mother of a child with FASD in Saskatchewan. The chapters that follow will provide a description of the literature on FASD and birth mothers of children with FASD, the methodology used in this research, and finally, the results of the research. The results are presented using the words of the women themselves and I have attempted to remain close to their experiences throughout the document.

Definition of Terms

The following definitions apply throughout this study and will be discussed in more detail throughout the document.

Fetal Alcohol Spectrum Disorder (FASD): An umbrella term used to describe the range of disorders caused by maternal alcohol consumption during pregnancy. FASD in itself is not a diagnostic term, but used to describe a range of diagnoses (Chudley et al., 2005).

Fetal Alcohol Syndrome (FAS): The most physically recognizable diagnosis under the FASD umbrella, FAS was first identified in 1973 (Jones & Smith, 1973). It consists of a specific pattern of defects, including facial abnormalities, impaired growth and central nervous system or neurobehavioural disorders (Chudley et al., 2005).

Partial Fetal Alcohol Syndrome (p-FAS): A second diagnosis under the spectrum of FASD, with characteristics including confirmed maternal alcohol exposure, some components of facial anomalies, and either growth retardation, neurodevelopmental anomalies or cognitive/behavioural abnormalities (Chudley et. al, 2005).

Alcohol Related Neurodevelopmental Disorder (ARND): A third possible diagnosis under the FASD umbrella, the diagnosis of which does not require any of the physical characteristics of facial anomalies or growth retardation. The diagnosis does require confirmed maternal alcohol exposure, evidence of neurodevelopmental abnormalities and cognitive or behavioural abnormalities (Chudley et. al, 2005).

Alcohol Related Birth Defects: A final diagnosis under the spectrum of FASD. Diagnostic criteria include confirmed maternal alcohol consumption and congenital anomalies (Chudley et. al, 2005).

Phenomenology: Phenomenology is both a philosophy and a qualitative approach to research and is based on the ideas and work of Edmund Husserl. As a research method, phenomenology has many different branches, but all focus on coming to a greater understanding of the lived experience of a phenomenon (Richards & Morse, 2007).

Hermeneutic Phenomenology: A form of phenomenology that is both descriptive, because it is attentive to how things appear; and also interpretive, as it claims there are no such things as un-interpreted phenomena. Hermeneutic phenomenology seeks to capture the “facts” of lived experience through interpretive language (van Manen, 1990).

Bracketing: Also known as epoché, this concept was developed by Edmund Husserl. It is the idea that in order to truly understand a phenomenon, a researcher must first set aside or “bracket” their own assumptions (Gall, Gall & Borg, 2007). Bracketing is a concept that is debated in modern phenomenology, and is used more frequently in some branches of phenomenology than in others (Langdridge, 2007).

Lived Experience: A phenomenological term which refers to the immediate, pre-reflective consciousness of life (van Manen, 1990).

Essence: A phenomenological term which refers to the universal structure underlying an experience (Langdridge, 2007). In a phenomenological study, the essence refers to a linguistic construction of a phenomenon (van Manen, 1990).

Protective Factors: "Protective factors refer to influences that modify, ameliorate, or alter a person's response to some environmental hazard that predisposes to a maladaptive outcome... the concept is not at all synonymous with a positive or beneficial experience" (Rutter, 1985, p.600)

Guilt: Guilt is conceptualized as an *adaptive* emotion concerned with an *action* which is a violation of a moral standard. Guilt has been associated with pro-social behaviour and actions which aim to repair the damage caused by one's behaviour (Dost & Yagmurlu, 2008; Nelissen & Zeelenberg, 2009).

Shame: In contrast to guilt, shame has been conceptualized as a *maladaptive* emotion concerned with *the self* in relation to an action which has violated a moral standard. Shame is considered to

invoke avoidance behaviours and withdrawal (Dost & Yagmurlu, 2008; Schmader & Lickel, 2006).

Stigma: A label which signifies that an individual has deviated from what society deems to be “normal”. Society responds to the label with reactions that serve to “...‘isolate’, ‘treat’, ‘correct’ or ‘punish’ individuals engaged in such behaviour.” (Schur, 1971, as cited in Simmonds & Coomber, 2009).

Healing: Responding to distress in a way that maintains functioning, but also moving beyond simply coping with stress to transformation, adaptation and transcendence (Gockel, 2009).

Coping Skills: Coping skills have been defined as “...conscious volitional efforts to regulate emotion, cognition, behaviour, physiology and the environment in response to stressful events or circumstances.” (Wadsworth & Compas, 2002). Coping skills are commonly divided into the categories of active and avoidant (Holahan & Moss, 1987) or “helpful and unhelpful” (Lauver, Connolly-Nelson & Vang, 2007).

CHAPTER 2

LITERATURE REVIEW

In this chapter I will provide a critical summary of the current research regarding Fetal Alcohol Spectrum Disorder (FASD), including of an overview of the research involving birth mothers of children with FASD. I will also review the relevant information regarding guilt and community stigma related to birth mothers of children with FASD. There is relatively little information available regarding guilt and stigma for birth mothers of children with FASD, therefore I will focus on guilt and stigma in parents of children with disabilities, as well as the general impact of guilt and stigma in the lives of individuals.

FASD General Information

Prevalence rates for FASD in Canada have not yet been established (Chudley et al., 2005), although based on data from the United States, the Public Health Agency of Canada has estimated that 9 babies in every 1,000 born in Canada have FASD (Public Health Agency of Canada, 2003). Prevalence rates have been established in certain areas of Canada. For instance, in high-risk communities it has been noted that the prevalence rates may be 1 in 5 (Health Canada, 2001). FASD is the leading cause of developmental disability among Canadian children (Public Health Agency of Canada, 2003) and the leading preventable cause of intellectual disability in the Western World (Grant et al., 2004).

FASD is a disability which is caused by maternal alcohol use during pregnancy (Chudley et al., 2005). Alcohol is a teratogen which passes through the placenta freely and can impact all parts of the developing fetus, particularly the central nervous system. The nature and extent of the damage will depend on which area of the body is developing when drinking occurs (Chudley et al., 2005). There are many factors beyond the use of alcohol that may impact the extent and nature of damage which occurs to the developing fetus, including maternal nutrition, the use of illegal drugs or nicotine, maternal health, metabolism of the mother and the fetus and prenatal care (Chudley et al., 2005; J. Salmon, 2008). There is no consensus on the amount of alcohol that is safe to drink during pregnancy. Contradictions occur across the world in regards to health recommendations. For example, in the United Kingdom, the Royal College of Obstetricians and Gynaecologists recommend no more than one standard drink per day, yet some current research suggests that there may be effects on the fetus resulting from that amount (J. Salmon, 2008). The current Health Canada recommendation is not to drink alcohol if you are pregnant, planning to

become pregnant or are sexually active and not using birth control (Public Health Agency of Canada, 2006).

Some researchers in recent years have been critical of this recommendation of abstinence from alcohol during pregnancy, stating that alcohol alone may not cause FAS (Abel, 1995; Armstrong, 2003; Schellenberg, 2007). They argue that the development of FASD may require a combination of factors such as malnutrition, smoking, stress and environmental toxins (Armstrong, 2003). Although alcohol is recognized as a teratogen, it may be this combination of toxins that lead to the development of FASD, and thus to the positioning of FASD as a “disease of the poor” (Toutain & Lejeune, 2008). Ernest Abel, an American researcher who is highly critical of the mainstream discourse surrounding FASD, states that “FAS is not an equal opportunity birth defect” in reference to the fact that rates of FAS are 10 times higher in sites characterized by low-socio-economic status than those of upper-middle socio-economic status (Abel, 1995). This discrepancy in rates between income groups will be discussed in further detail in the section on risk factors for birth mothers of children with FASD.

Diagnostic Considerations

Although the damages caused to unborn children by the use of alcohol have been noted throughout history, it wasn't until 1968 that the damage was discussed in medical literature by the French researcher Lemoine and colleagues (Calhoun & Warren, 2007). The term Fetal Alcohol Syndrome was coined in 1973 in the United States to identify a pattern of anomalies presented in children of alcoholic mothers (Jones & Smith, 1973). The group of characteristics that were identified as common to the children studied included developmental delay, microcephaly, growth deficiency, short palpebral fissures, epicanthal folds, small jaws and flattened midface, joint anomalies, and altered palmer crease patterns (Calhoun & Warren, 2007).

Over time, it became evident that effects could be seen in the absence of all of the physical characteristics of FAS, thus the term Fetal Alcohol Effects (FAE) was coined to encompass the full spectrum of possible effects (Chudley et al., 2005). In 2005 the term FAE was replaced by several other diagnostic categories and the term Fetal Alcohol Spectrum Disorder (FASD) was created to describe the new categories (Chudley et al., 2005). The term FASD is not a diagnosis in itself; it is an umbrella term used to describe the range of disabilities caused by prenatal exposure to alcohol. Throughout this document I will use the term FASD to refer to individuals

with any of the diagnoses under the spectrum of prenatal exposure to alcohol. If specific diagnostic terms such as FAS are used in the discussion of previous research, I am using that term to describe the exact population that was involved in the study.

Diagnosis of FASD in Canada is a multi-disciplinary process, involving a neuro-behavioural assessment and an exam by a physician trained in the diagnosis of FASD (Chudley et al., 2005). There are four categories of diagnosis under the spectrum of FASD. The first is Fetal Alcohol Syndrome (FAS). This diagnosis may be given with or without confirmed maternal alcohol use during pregnancy. In this diagnosis and all other diagnoses under the spectrum of FASD, maternal alcohol consumption during pregnancy is confirmed through clinical observation, self-report by the mother, or another reliable source such as medical records (Chudley et. al, 2005). The diagnosis of FAS must include three features: a characteristic pattern of facial anomalies; evidence of growth retardation; and evidence of central nervous system neurodevelopmental abnormalities. The specific neurodevelopmental abnormalities include decreased cranial size at birth, structural brain abnormalities or neurologic hard or soft signs (Chudley et al., 2005). The second possible diagnosis is partial-Fetal Alcohol Syndrome (pFAS). This diagnosis requires confirmed maternal alcohol exposure, some components of the characteristic facial anomalies, and either growth retardation, neurodevelopmental abnormalities, or a complex pattern of behaviour or cognitive abnormalities. These include deficits in learning, school performance, impulse control, social perception, receptive and expressive language, or problems with abstraction or metacognition (Chudley et al., 2005).

The third possible diagnosis is Alcohol-related birth defects (ARBD), with requires both confirmed prenatal alcohol exposure and congenital anomalies including cardiac, skeletal, renal, ocular or auditory deficits (Chudley et al., 2005). The final diagnosis is Alcohol Related Neurodevelopmental disorder (ARND). This diagnosis requires confirmed maternal alcohol exposure and the presence of neurodevelopmental abnormalities or a pattern of behaviour or cognitive abnormalities (Chudley et al., 2005). These diagnostic categories are common throughout the world, but the process of arriving at the diagnosis varies. Commonly used in the United States is the 4 Digit-Diagnostic Code, a tool consisting of Likert-scale items, the scoring of which result in a code which determines diagnosis (Coggins, Timler, & Olswang, 2007).

Fetal Alcohol Syndrome is the presence of all characteristics of the disorder. A diagnosis of p-FAS or ARND may reflect a lower dose of alcohol, but it also may reflect differences in the

timing of alcohol ingestion, maternal metabolism or interactions with other environmental exposures (Sampson et al., 1997). A diagnosis of p-FAS or ARND does not equate to less damage to the brain; the main difference is a lack of the physical characteristics (Chudley et al., 2005). Children without the physical characteristics have been shown to have the same deficits on neuropsychological and behavioural measures as children with FAS (Sampson et al., 1997). Furthermore, a 2004 study found that individuals with a diagnosis of FAE (now equivalent to p-FAS or ARND) had higher levels on five different adverse outcomes than those with a diagnosis of FAS (Streissguth et al., 2004). It has been suggested that this discrepancy may be due to the fact that individuals diagnosed with FAS qualify for more services than do individuals with the other diagnoses (Streissguth et al., 2004).

Characteristics

Since the effects of prenatal alcohol exposure are varied, there are many characteristics displayed by individuals with FASD. Impairments are often seen in executive function (Connor, Sampson, Bookstein, Barr, & Streissguth, 2000; McGee, Fryer, Bjorkquist, Mattson, & Riley, 2008; Paley, O'Connor, Frankel, & Marquardt, 2006), cognitive ability (Olson, Feldman, Streissguth, Sampson, & Bookstein, 1998), learning and behaviour (Streissguth, 2007) and impulse control (Connor et al., 2000; Streissguth, 2007). Many individuals with FASD also display an inability to learn from consequences, speech and language or visio-spatial deficits, deficits in spatial memory or verbal learning, impulsivity, poor judgement, a lack of cognitive flexibility, and an inability to generalize rules or understand social interactions (Green, 2007).

Deficits in executive functioning may account for many of the life struggles faced by people with FASD (Watson & Westby, 2003). Executive functioning can be defined as “a group of control functions that direct and regulate cognitive behaviour as well as social behaviour” (Watson & Westby, 2003). Deficits in executive functioning are present with or without the presence of an intellectual disability. Prenatal exposure to alcohol has been found to depress intellectual ability, but most individuals with FASD fall in the borderline to low average intellectual ability range (Streissguth et al., 2004). It has also been found that intellectual ability level does not predict functioning in individuals with FASD (Connor et al., 2000; Olson et al., 1998) and deficits in adaptive functioning and cognitive tasks such as memory, reading and attention exist with or without the presence of an intellectual disability (Olson et al., 1998).

The characteristics and disabilities described above are those which are a direct result of damage to the developing brain during pregnancy. They have therefore been labelled as the “primary disabilities” of FASD (Streissguth, Barr, Kogan, & Bookstein, 1997). This distinguishes them from “secondary disabilities”, which include the range of problems that affect many individuals with FASD. Secondary disabilities were first identified by a group of researchers in Seattle, Washington through the study of a group of 415 individuals living with FASD (Streissguth et al., 1997). Common secondary disabilities include mental health problems; disrupted school experiences; trouble with the law; confinement in prison; inappropriate sexual behaviour; drug or alcohol problems; trouble with employment; homelessness; and being the victim of abuse (Streissguth et al., 1997).

There have been several studies of the prevalence of secondary disabilities among individuals with FASD (Streissguth et al., 2004; Streissguth et al., 1997). The above 1997 study identified rates for eight different secondary disabilities among 415 individuals diagnosed with FAS or FAE. The individuals involved in the study were between the ages of 6 and 51 at the time of the study. The rates of secondary disabilities were as follows: mental health problems were identified in 90% of the group; disrupted school experiences by 60%; trouble with the law by 60%; confinement was experienced by 50% of the sample; inappropriate sexual behaviours were found in 50% of the sample; alcohol and drug problems were found in 37% of the sample. Among the adults in the study, 80% were in a dependent living situation and 80% had experienced problems with employment (Streissguth et al., 1997). The study demonstrated that most individuals with FASD experience some or many of these secondary disabilities throughout the lifetime.

A 2004 study examined that same data and reported the findings of rates of secondary disabilities among the different age groups of individuals in the study (Streissguth et al., 2004). The prevalence of secondary disabilities was described according to the age categories of children, adolescents and adults. Inappropriate sexual behaviours was found to increase from 39% to 47% to 51% across the three age categories. Disrupted school experiences were found in 14% of children, 62% of adolescents and 59% of adults. Trouble with the law had been experienced by 14% of children, 61% of adolescents and 58% of adults. Confinement was experienced by 8% of children, 46% of adolescents and 57% of adults. Alcohol and drug problems had not yet been experienced by any of the children in the study, but had been

experienced by 29% of the adolescents and 45% of the adults. Although not identified as a “secondary disability”, it was found that 61% of children, 70% of adolescents and 73% of adults had been the victim of physical or sexual abuse, or domestic violence (Streissguth et al., 2004). This further examination of the data revealed how the rates of secondary disabilities can increase throughout the lifetime.

Risk and Protective Factors

Although the primary disabilities associated with FASD are present from birth, the secondary disabilities develop over the lifespan and their impact can be reduced. The same 2004 study described above (Streissguth et al., 2004) also compared the presence of certain life experiences with the presence of secondary disabilities, with the hopes of discovering protective factors to diminish the likelihood of the adverse outcomes in individuals with FASD. Multiple regression analyses were used to compare the presence of five different secondary disabilities with a variety of risk and protective factors, including personal characteristics such as gender and age at diagnosis, and environmental characteristics such as time spent in a stable and nurturing home and amount of time spent per household (Streissguth et al., 2004). The variable which was most highly predictive of secondary disabilities was time spent in a stable and nurturing home. A large amount of time in a stable and nurturing home reduced the risk for four out of the five secondary disabilities examined. The second variable which was found to be significant in the prediction of secondary disabilities was time at diagnosis; the longer the delay in diagnosis, the larger the risk of adverse outcomes (Streissguth et al., 2004). Early diagnosis and a nurturing home may both depend on the experiences and abilities of the birth mothers of these children with FASD. A better understanding of the experiences of birth mothers of children with FASD may help in understanding the barriers to achieving these protective factors in the lives of women and their children.

Birth Mothers of Children with FASD

There is limited available information regarding the experiences of birth mothers of children with FASD. The majority of information that is available is quantitative and descriptive in nature. Most studies have also been designed with the intent of describing the characteristics of women who may be at risk of giving birth to a child with FASD, with the overall goal of prevention in mind. There are few quantitative or qualitative studies available focusing on describing the lives of women after the birth of their child or during the process of mothering. I

will thus discuss some of the statistics available which describe this group of women, and critically evaluate the qualitative studies that have been published. I will then provide an overview and critique of the risk factors that have been found to be predictive of having a child with FASD.

Characteristics

Birth mothers of children with FASD have been found to have high rates of poverty, abuse, mental health disorders and low education (Astley, Bailey, Talbot, & Clarren, 2000b; May et al., 2005; May et al., 2008). They have also been found to be at high risk for early mortality (Berg, Lynch, & Coles, 2008). Although there has not been a great deal of research conducted with birth mothers of children with FASD, several profiles are available from studies in the United States. A two part study in the United States in 2000 sought to identify potential birth mothers of children with FASD and provide a comprehensive profile of the population (Astley, Bailey, Talbot, & Clarren, 2000a; Astley et al., 2000b). The first study suggested that an effective way to identify women who are at-risk of having a child with FASD and in need of preventative programming was through the previous diagnosis of another child (Astley et al., 2000a). The study concluded that this is an important group of women to identify for preventative programming as successive pregnancies often result in children who are more severely affected (Astley et al, 2000a).

The second half of the study provided a profile of the women who had been identified through the diagnosis of a child (Astley et al., 2000b). The women who were identified had given birth to a child who had been diagnosed with either FAS or static encephalopathy, alcohol exposed (an alternative diagnosis before the development of the current diagnostic categories). A profile of the 80 women who fit this category was developed. The average age of the women at the birth of the diagnosed child was 27, and 38 years old at the time of the study. On average, the women were 15 years of age at the time they started drinking and were drinking most heavily between the ages of 23 and 28. The ethnicity distribution of the women was 67% caucasian, 6% African-american, 24% American Indian/Canadian and 1% Hispanic. The average IQ of the women was 90. Sixty one percent of the women had not finished high school, and 25% had some college education. At the time of the birth of their child, 78% of the women had lived on an income of less than \$10 000 US per year. Shockingly, 95% of the women had been physically or sexually abused and 96% had between 1 and 10 mental health disorders. The majority of the

pregnancies (73%) had been unplanned and 94% of the women stated that they did not want to reduce their alcohol use during pregnancy because it helped them cope. At the time of the study, 62% of the women were abstinent from alcohol. Compared to the group of women who were still drinking at the time of the interview, the women who had achieved abstinence had higher intellectual abilities, higher income levels, more social support, more likely to report religious affiliation and more likely to have received treatment for a mental health disorder. This study provided a basic description of the lives of typical birth mothers of children with FASD in the United States. Similar data from Canada would be helpful in furthering our understanding of the experience of being a birth mother of a child with FASD. Moreover, this type of description provides a starting point in understanding, more detailed descriptions of these women's lives are needed to inform programming for the women and their children.

Experiences of Birth Mothers of Children with FASD

As of 2008, there have been two studies in the academic literature which have examined the experiences of women since the birth of a child with FASD (A. Salmon, 2007; J. Salmon, 2008). The first article was a part of a dissertation which deconstructed the government of Canada's document, "The First Nations and Inuit Fetal Alcohol Syndrome/ Fetal Alcohol Effects Initiative" from a feminist, anti-racial and anti-colonial perspective (A. Salmon, 2007). The author, Amy Salmon, sought to understand how the nation-state constructs and positions Aboriginal women in the context of FAS/E and how the official knowledge produced by the government's "Initiative" impact the resources available to Aboriginal mothers and people living with FASD (A. Salmon, 2007). In order to gather information on how these forms of knowledge impact Aboriginal mothers, Salmon conducted focus groups with six young urban Aboriginal mothers in British Columbia whose lives include substance use and FASD. All six of the women involved admitted to using substances during pregnancy, although it does not seem that a diagnosis of FASD for their child was required for participation in the study.

The article published from this dissertation deals with how the voices of Aboriginal women are neglected in the analysis and policy development around FASD prevention (A. Salmon, 2007). Although the study does not focus specifically on the experiences of the women themselves, it makes several important contributions to understanding where birth mothers of children with FASD are situated in Canadian society, especially in terms of race, gender and power. Aboriginal birth mothers of children with FASD are presented as making individual

choices which lead to their children's disabilities, and these choices are removed from experiences of trauma, abuse and systemic racism in Canadian discourse (A. Salmon, 2007). Salmon gives important insight into how women are silenced and blamed for FASD in Canadian society, but does not delve deeply into how that blame and stigma impacts the women's daily lives and interactions with their children. In this study, I seek to gain a deeper understanding of the experience of being a birth mother of a child with FASD within this societal context.

The second qualitative study included interviews with mothers of children with FASD in New Zealand, with a focus on their experiences since the birth of their child (J. Salmon, 2008). Using a feminist standpoint and unstructured interviews, the author, Jenny Salmon, gathered the stories of eight birth mothers of children with FASD in New Zealand regarding their experiences from pregnancy onwards. The women involved in the study were between the ages of 29 and 64. Considering the similar question, participants and methodology of J. Salmon's study to my own, I will describe the findings of that study in detail.

Using the constant-comparison method of data analysis, J. Salmon discovered four re-occurring themes throughout the women's experiences. The first theme struck me as it related closely to the inspiration for this study, entitled "It's all the Mothers fault." J. Salmon identified recurrent statements from the data regarding experiences of blame from others, and feelings of personal responsibility for the child's disability. Interestingly, although all the mothers felt responsible for their child's disability, not all felt guilt (J. Salmon, 2008). This is a concept which I sought more information about in this research context.

The second theme identified by J. Salmon (2008) is one of abandonment by medical health professionals. The mothers felt that they were not supported, not listened to and abandoned by health professionals. From the women's perspectives, health professionals treated them with judgement and negative attitudes (J. Salmon, 2008). Two women discussed negative remarks they had received from their general practitioners when consulting about problems with their children with FASD. This abandonment by professionals and its relationship to judgemental attitudes is relevant to my study and is related to many of my assumptions regarding blame and stigma in the community. More information regarding how birth mothers experience this prejudice is needed in order to provide birth mothers with appropriate interventions for themselves and their children.

The third theme identified by J. Salmon (2008) was related to a lack of support in the educational system. They felt that the schools had few interventions which supported their child and that the teachers viewed them negatively and without empathy. The women expressed that they and their children were viewed as a burden on the educational system and that their children's behaviour was not understood by teachers. The mothers also talked about the need for their children to be taught according to their needs and to be included in the classroom. In this third theme, I again see an emphasis on a perception of negative community attitudes and unwillingness to support the women and their children.

Finally, the fourth theme identified blame on the mothers regarding the criminal behaviour of their children. The mothers identified that they felt blame from the police in statements such as "why weren't you watching him," (J. Salmon, 2008, p.204). The mothers also talked about the police being uneducated regarding FASD. Looking at the four themes resulting from the experiences of the women in New Zealand, I notice several important findings relevant to my own study. First, the common thread that I see through all four themes is the idea of blame. The prejudices perceived by the birth mothers involved in this study were vast. I am interested in whether I will find similar experiences among women in Canada and how this relates to their experiences as a birth mother of a child with FASD. Secondly, the women in J. Salmon's study were able to articulate several of their children's needs in terms of interventions. The women were also described as amazing advocates for their children (J. Salmon, 2008). This knowledge of their own children's needs and ability to advocate tells me that it is extremely important to hear the voices of birth mothers of children with FASD in Canada; their direct experiences with their own children may be one of the most important sources of information for those creating policy and interventions.

Another discussion of the experiences of mothers of children with FASD is available online in the form of a photovoice project carried out in Ontario, Canada. The project is entitled "Picture This: Life as a Parent of Children with FASD (Fetal Alcohol Spectrum Disorder)" (Healthy Generations Family Support Program, 2008). The project involved a group of women who were birth, adoptive and foster mothers of children with FASD. The mothers were asked to take pictures which represented their lives as caregivers of children with FASD. In group discussions, the women identified issues and troubles in their lives and the lives of their children with the help of the photos they had taken. The project is presented as a slide show of the

pictures, and voice-overs from the women provide a description of what each picture represents. A birth mother who participated in the project, Deyanna, described the picture of rain falling down a window which she had labelled “Overflow,” as follows:

The eaves were filled with muck leaves and branches; rotting there, like the guilt that eats away at me. And when it rained really hard the water couldn’t flow properly down the drain. It overflowed in just the same way the guilt, anger and sadness have been overflowing out of me. Crying brings the release of emotions and the hope of healing and forgiving myself because it’s still hard to say out loud. Admit I know that my son has FASD because I know it’s my fault. I am living with what I have done to my child. It confronts me every day in his behaviours. His intense emotions and his frustrations with himself. When people look at me will they see a mother who loves her child or a woman who did this to her child? Will my child forgive me? I look at the water falling in this picture and it’s beautiful, but there is a feeling of hope mixed with fear of the unknown too. (Healthy Generations, 2008)

The emotions identified by Deyanna speak for themselves. More information is needed from birth mothers of children with FASD in Canada regarding these experiences. One concept which is brought up by Deyanna on which there is no literature available is the idea that the mother could be constantly be reminded of her guilt through her child’s struggles.

A dissertation written by Dorothy Badry (2008) offers insight into the life experiences of birth mothers of children with FASD. In a hermeneutic phenomenological study, Badry describes the journeys of eight women in Alberta as they “became” a birth mother of a child with FASD. Badry presents an overview of each woman’s personal story, using key words to highlight each woman’s experience. Badry then goes on to identify themes that were common to the experience of becoming a birth mother of a child with FASD. She identified themes related to the women’s relationships with their families; the women’s struggles with alcohol; a history of trauma; the experience during pregnancy; the woman’s relationship with the birth father; the involvement of child welfare; and the meaning that the women make in having a child diagnosed with FASD (Badry, 2008).

Many of the women reported early experiences with alcohol within their families and their own early use. Trauma and violence was discussed by all but one of the women, and played a large role in the experience of becoming a birth mother of a child with FASD (Badry, 2008). The experience with the birth father is also identified as very influential in becoming a birth mother

of a child with FASD; many of the women had been abused by the father of the child before and during the pregnancy. Of the eight women interviewed, only one birth father was currently involved in the child and woman's lives (Badry, 2008). A finding that was vital to understanding substance abuse and the prevention of FASD was the women's experiences of pregnancy. Pregnancy for many was a time of broken life experiences contrasted with hope and promise for the future (Badry, 2008). Many of the women sought to stop drinking alcohol when they found out they were pregnant, some did and some could not. What is important is that pregnancy was seen as a turning point for many of the women, a suggestion that has been echoed by others (Weaver, 2007). Support during pregnancy which is non-judgemental and comprehensive could promote better outcomes for both women and their children (Boyd, 2007a, 2007b).

Badry uses a feminist framework to present the women in her study as strong and resilient survivors. Although the women identified feelings of self-blame and struggles with their children, they also presented as strong mothers who viewed their children as unique individuals, not as "tragedies" (Badry, 2008, p. 194). Badry identified the importance of more research being conducted regarding the meaning that the women make regarding the diagnosis of their child, something which I hoped to shed more light upon within this study. The strength of the women who shared their stories with Badry is inspiring. In this study, I hoped to build on the knowledge created by Badry and her participants; learning more about the experiences of the women since the birth of their child, especially in terms of guilt and stigma. These few studies discussed some of the common experiences of birth mothers of children with FASD, another commonly studied area involves the risk factors in becoming a birth mother of a child with FASD.

Risk Factors

One of the largest areas of research regarding FASD revolves around prevention, and what risk factors can be identified in women that place them at risk for having a child with FASD. As mentioned briefly above, one major factor which has been identified as placing women at risk for having a child with FASD is the diagnosis of a previous child (Astley et al., 2000b). Other general risk factors for women that have been identified include heavy binge drinking with high levels of blood alcohol concentration (BAC); low socioeconomic status; advanced maternal age; unstable marital relationships; the use of cigarettes or other drugs; high scores on alcohol abuse assessment tools; inadequate nutrition; poor access to prenatal care; and having an alcoholic partner (Chudley et al., 2005; May et al., 2005). Although these risk factors have been

identified, to date there is no single factor that has been found that distinguishes women who will have a child with FASD from those who may drink during pregnancy but have a “normal” child (Astley et al., 2000a).

A three-part study of birth mothers of children with FASD was conducted by a group of researchers in South Africa with the goal of discovering risk factors for women in having a child with FASD. The studies were unique in that the population from which the participants were drawn from was a town which suffers from the legacy of what was called the “Dop” system, in which labourers on grape farms and wineries were partially paid in alcohol. Although not practiced currently, this system has resulted in a community with generational alcohol abuse problems (May et al., 2005; May et al., 2008; Viljoen, Croxford, Gossage, Kodituwakku, & May, 2002). In a case-control design, mothers of children with FASD were compared with mothers of children who did not have FASD. All mothers were interviewed and information was gathered regarding all areas of life, including their pregnancies, alcohol use and socio-economic status. Because all women were from the same community with high levels of alcoholism, the majority of both groups of mothers drank alcohol during pregnancy. However, when compared to the control group, the mothers of children with FASD were more likely to describe their pregnancy as a stressful time in life, were more likely to have increased drinking during pregnancy and were more likely to have smoked during pregnancy (Viljoen et al., 2002). Both groups of mothers were from socially disadvantaged and poverty stricken backgrounds, but the mothers of children with FASD had the lowest socioeconomic status and the least social resources (May et al., 2008). The birth mothers of children with FASD were also more likely to be unmarried and have heavy drinkers in their family, as well as heavy drinking partners. Although these risk factors were identified in South African women, many correspond with the characteristics of the women who have been described in the United States (Astley et. al, 2000b).

Socioeconomic status is noted frequently as a maternal risk factor for having a child with FASD (Astley et al., 2000b; May et al., 2005; May et al., 2008), as can be seen in the above studies from South Africa and America. Without examining the other factors that influence the development of FASD and how those are related to poverty, there is a danger of labelling FASD as a “tragedy of the poor” as in one recently published academic article (Toutain & Lejeune, 2008, p.426). While it is important to note the high rates of FASD among low socio-economic

groups, one must always consider the factors which are associated with poverty and also increased risk of harm from prenatal alcohol exposure.

A 1987 study (Bingol, Schuster, Fuchs, & Iosub) found significantly higher rates of FAS and similar effects among a low socio-economic group of women when compared to a higher socio-economic status group of women who had all consumed alcohol during pregnancy. Importantly, the study pointed out that nutrition may have played an important factor in this difference, since the women in the higher socio-economic status group ate more regularly, ate a more balanced diet and supplemented their diet with vitamins (Bingol et al., 1987). Recent research with laboratory rats has provided evidence that under-nutrition contributes to a lower rate of alcohol metabolizing and to higher levels of blood alcohol concentrations in pregnant rats (Shankar, Ronis, & Badger, 2007). The importance of nutrition among these most impoverished and at-risk women cannot be underestimated, as poor nutrition and lack of food contributes to higher blood alcohol levels, which are linked to higher rates of FASD (May et al., 2008).

By stating that socio-economic status is a risk factor, without considering the implications and connections behind that statement, women living in poverty are simply blamed for being the problem, rather than part of a complex web of interconnected factors. In order to move beyond blame, it is important to recognize the interconnected risk factors and life situations which lead to women living in poverty having higher rates of children with FASD. Women in lower socio-economic status groups have higher rates of births of children with FASD, but this is due to a variety of factors that impact the health of the woman and her baby, including inadequate nutrition, tobacco and other drug use, environmental contaminants and high parity (Tait, 2003). Also, if we study these statistics from a feminist standpoint, we recognize that although substance use is presented as an individual and deliberate choice, women's actions and decisions occur within the context of relations to others and the community (Marcellus, 2007).

One of the most contentious, as well as most misunderstood, risk factor for women in giving birth to a child with FASD is race. Many studies identify specific races as a risk factor for having a child with FASD without situating the discussion of race within the broader societal context (Morris, Tenkku, Salas, Xaverius, & Mengel, 2008; Viljoen et al., 2002). In doing so, authors may again contribute to damaging stereotypes, and place the blame of FASD on women of specific ethnicities. It is noted within the Canadian diagnostic guidelines that it is a common misconception that FASD is associated with specific ethno-cultural backgrounds. More

important, the article states, are issues of maternal age, education level, socio-economic status and the other risk factors discussed above (Chudley et al., 2005). When a control group of women in South Africa was compared to a similar group who were birth mothers of children with FASD, the race and socio-economic status of the two groups was almost identical; what was found is that the most severe life circumstances produce more problem drinking and more FASD (May et al., 2008; Viljoen et al., 2002). It has been asserted that race may not be as important a risk factor as is socio-economic status, which as described above, allows other factors such as low nutrition to compound effects on the fetus (Abel & Hannigan, 1995; Nanson, 1997).

Rates of FASD have been found to be higher among certain ethnicities, for example, in Canada, rates of FASD in Aboriginal communities have been found to be almost ten times the rate of the general population (A. Salmon, 2007). However, the concept of race must be situated in the larger social context of oppression, power and control and social positions. Statistics must be interpreted with the understanding of the life circumstances which many Aboriginal individuals face in communities suffering from the impact of residential schools and generations of oppression. Tait (cited in A. Salmon, 2007), states "... chronic poverty and social marginalization appear to be variables more important to identifying women at risk than ethnic identity. Because Aboriginal women are the poorest and most marginalized group in Canada these factors, rather than their Aboriginal culture or heritage, situate them among women at risk" (174). Abel (1995) suggests that:

The major determinant for the occurrence of FAS is poverty. FAS is more common among minorities in the inner cities of the United States, not because some minorities are genetically at-risk for FAS but because a high percentage of minority women eke out an existence at incomes below the poverty line ... Poverty, not genotype, provides the kind of host environment that exacerbates alcohol's toxic actions." (p.441).

When race is considered as a risk factor without discussing the situation of different races within society, there is a risk of blaming specific races for the problem of FASD. A recent study examined variables which influence the reduction of drinking during pregnancy in the United States (Morris et al., 2008). Within the sample of women in the study, the white women had higher levels of education, higher levels of income and were more likely to be married (Morris et al., 2008). Several variables were found to be related to a greater reduction of drinking during

pregnancy, including education, age and race (Morris et al., 2008). These variables are discussed within the article as if they had no relation to each other. The authors state “We found that White women appear more likely than Black women to reduce drinking and binge drinking upon becoming pregnant... this finding may help explain disparities in FAS rates between White and Black populations.”(Morris et al., 2008, p. 510). This statement is made without any reference to the differences in socio-economic status and education of the women in the study. Although age and education were also significantly related to a reduction in drinking during pregnancy, only race is named as a factor in both the title and the abstract of the article (Morris et al., 2008). This article is an example of how research can be used to preserve stereotypes about racial differences when race is not contextualized within the society in which it exists.

It is recognized as common knowledge in Canada that FASD is more prevalent in Aboriginal communities. However, Caroline Tait (2003) presents a critique of this “knowledge” through a deconstruction of the assumptions that have led to this conclusion. Tait argues that there are no known prevalence rates for FASD among Aboriginal communities in Canada, and that the research processes and policies surrounding FASD have led to the over-detection of FASD among Aboriginal peoples. This over-representation of Aboriginal peoples may be based upon a detection bias, in which Aboriginal peoples are more likely to be screened and identified for diagnosis of FASD (Tait, 2003).

A further critique of the “knowledge” that rates of FASD is higher among Aboriginal populations, is that the standards of physical measurements used to diagnose FASD are not based upon standard measurements from the Aboriginal populations. Dr. Jo Nanson, a prominent FASD expert in Saskatoon, stated:

The facial dysmorphology in native children with FAS can be somewhat confusing as many aboriginal children have epicanthus and a depressed nasal bridge. This appears to occur so commonly in aboriginal children that the physicians I work with feel it is simply a genetic variant and is not representative of fetal alcohol syndrome” (Nanson, cited in Tait, 2003, p. 148).

Misclassification may also occur in the use of growth retardation as another physical characteristic used to diagnose FASD. Many Aboriginal children living in poverty may be below height and weight norms due to malnutrition; this may lead to an over-diagnosis of FASD among this population (Tait, 2003).

This section has outlined some of the research with birth mothers of children with FASD. Another piece of understanding that seems to be missing in the literature is information regarding parenting and mothering by birth mothers of children with FASD. The following section will outline some of the available information on parenting children with FASD by both birth mothers and other caregivers of children with FASD.

Parenting Children with FASD

An important aspect of the experiences of birth mothers of children with FASD is experiences mothering a child with FASD. What is it like to mother a child with FASD? What is that experience like for a birth mother? The birth mother in the photovoice project described previously mentioned that her actions and guilt confronted her every day in her child's behaviours (Healthy Generations, 2008). I question how the interaction of feelings of guilt and perceptions of stigma play out in the experience of mothering for birth mothers of children with FASD.

Parenting a child with a disability carries many difficulties, and those difficulties are intensified for birth mothers of children with FASD considering their life situations and the shame and stigma attached to the diagnoses of FASD. Dorothy Badry, researcher and mother of a child with a disability, notes that her experience in being a birth mother of a child with a genetic disability is likely to be very different than that of a birth mother of a child with FASD, since she is not blamed for causing her child's disability (Badry, 2008). In a discussion with doctors regarding views of FASD, Elizabeth Armstrong quotes one doctor as stating "with most genetic diseases, you spend a lot of time discussing the fact that the patient's not to blame for it, for a genetic problem, these are random [events]. And you know in this situation you are talking about, yeah, somebody is to blame" (Armstrong, 2003). The experience of giving birth to and mothering a child with FASD is likely very different than the experience of mothers of children with other disabilities. It is also likely to be very different experience for a birth mother when compared to an adoptive or foster mother because of this shame and blame which is attached to the diagnosis. This experience of mothering as a birth mother of a child with FASD needs to be understood in greater detail. In the following section, I will first present an overview of the literature that is available on the experience of parenting a child with FASD, followed by an overview of the common assumptions regarding the parenting ability of birth mothers of children with FASD.

Experiences of Parents of Children with FASD

Several studies have been conducted on the experiences, needs and stresses associated with being a parent of a child with FASD. Since children with FASD have a variety of behavioural and cognitive problems, parenting can present difficult challenges on a daily basis. Higher levels of behavioural and emotional problems in children with FASD are related to higher levels of parental stress (Paley et al., 2006; Paley, O'Connor, Kogan, & Findlay, 2005). A qualitative study with adoptive parents of children with FAS in the United States demonstrated that parents saw their lives as changed and “like no one else’s” when raising a child with FASD (Clement-Murphy, 2001, p.34). The parents involved in that study discussed themes related to people not understanding their child’s disability; their children not learning from consequences and struggling with lying and stealing; and the unpredictable nature of their lives (Clement-Murphy, 2001). A similar study with foster parents caring for children with FAS found that the parents struggled to cope on a daily basis, discussing the need for consistency, fears for their child’s future and the coping strategies to parent a child with FAS (Gardner, 2000). The nature of the disability of FASD seems to create stress and chaos in the lives of parents.

A stable and nurturing home was found to be one of the protective factors for children with FASD in reducing the impact of secondary disabilities (Streissguth et al., 2004). In order for that to be possible, parents of children with FASD need supports, education and interventions to reduce stress and provide a consistent and stable environment. A 2003 study with nineteen caregivers parenting children with FASD in Canada asked participants to share what is needed in order to be a good parent of a child with FASD (Brown & Bednar, 2003). Among the participants were sixteen foster parents, eight adoptive parents and two birth parents. The needs that were identified included support of family and friends; professional supports; collaboration with the school; responsive and coordinated health and social services; the ability to view the child as an individual; good child management skills; and the right personality characteristics, including patience and tolerance (Brown & Bednar, 2003). Greater understanding of how the needs of caregivers of children with FASD, and birth mothers in particular, may assist the provision of safe and nurturing homes for children with FASD.

Birth Mothers as Parents: “Bad mothers”

Caroline Tait (2003) describes how the diagnostic definitions of FASD place blame on the mothers of children with FASD and add to the discourse in Canada which describes

Aboriginal women as “bad mothers”. Armstrong (1998, 2003), takes a similar argument regarding all birth mothers of children with FASD, stating that the diagnosis of FASD is a “moral stigmatizing category” (1998, p. 2035), used to diagnose the mother as an alcoholic and present the child and the mother as social and medical problems. This representation of women who use substances during pregnancy as “bad mothers” and “social problems” depicts women as the individual causal factors behind a birth defect which occurs predominantly in women living in poverty (Schellenberg, 2007). By presuming that the mother’s behaviour needs to be controlled, attention is taken away from the need to address the social and environmental factors that contribute to FASD (Schellenberg, 2007).

The view of women who use substances during pregnancy as “bad mothers” may contribute to birth mothers’ experiences of mothering in several ways. One experience which is likely common to birth mothers of children with FASD is the involvement of child protection services. Weaver (2007) describes the relationship of mothers who abuse substances and child protection workers as being adversary and “governed by fear” (p.80). Many children are removed from their mothers at birth when substance use during pregnancy is suspected (Boyd, 2007a). This results in a situation in which birth mothers are rarely the main parent involved in their child’s lives (Clement-Murphy, 2001). In a study with 61 adolescents and adults with FASD, only 3% were currently living with their biological mothers and almost one third had never lived with their biological mothers (Streissguth, Barr, Kogan, & Bookstein, 1996, cited in Gardner, 2000). Susan Boyd (2007a) describes the child protection workers in Vancouver as believing that women who used illegal drugs were incapable of parenting and that permanent child apprehension was “the norm rather than the exception for poor women suspected of illegal drug use” (Boyd, 2007a, p. 11). There is a common myth in our society that drug and alcohol abusing women are neglectful and unfit mothers (Arendt & Farkas, 2007; Badry, 2007; Eliason & Skinstad, 1995; Poole & Isaac, 2001). The experience of relating to child protection services is likely to be present for many birth mothers of children with FASD.

This adversarial relationship between child protection services and substance using mothers contributes to birth mothers hiding their substance use and not coming forward to seek treatment for fear of losing their children (Badry, 2007; Poole & Isaac, 2001). Drug and alcohol treatment centres were historically developed for men with alcohol problems and often do not accept women with their children into the programs (Arendt & Farkas, 2007; Marcellus, 2007). The

result is that many birth mothers continue to use alcohol while parenting their children and this will in turn affect their relationship with their children and the experience of mothering.

As demonstrated by the studies with adoptive and foster parents, any person raising a child with FASD is likely to have considerable difficulties; however it is asserted that the challenge is even greater if the parent also has to deal with their own problems with alcohol abuse (Arendt & Farkas, 2007). Women with addictions face a variety of unique barriers to parenting, including a lack of social support, high levels of depression and low self-esteem, high levels of domestic abuse and possible cognitive deficits associated with long-term substance abuse (Eliason & Skinstad, 1995). All of these factors are associated with impaired parenting, suggesting the need for parenting support along with addictions treatment (Eliason & Skinstad, 1995). When pregnant women and mothers are provided with comprehensive and non-judgemental care, better outcomes are possible for both the women and their children (Boyd, 2007a, 2007b).

Shame and Guilt

Although qualitative analyses with birth mothers of children with FASD are minimal, the few studies that have been completed have all pointed to internal feelings of guilt or shame as a theme which is common to this lived experience (Healthy Generations, 2008; A. Salmon, 2007; J. Salmon, 2008). Guilt was described as a major theme for the birth mothers interviewed in New Zealand (J. Salmon, 2008) and several birth mothers of children with FASD in Canada have identified guilt as a factor in their lives (Badry, 2008; Healthy Generations, 2008). Badry (2008) identified feelings of shame and guilt as a part of the meaning which birth mothers make in having a child diagnosed with FAS. One woman involved in that study stated that “There is nobody that puts them self down more than me for doing what I did. I have harmed them” (Badry, 2008, p. 185).

These feelings of shame may impact the lives of birth mothers and their children in many ways. Pregnant and parenting women accessing substance abuse treatment have identified several primary barriers to accessing treatment including shame, fear of losing their children, and fear of prejudiced treatment based on their status as pregnant or mothering (Poole & Isaac, 2001). Mothers of children with a variety of disabilities often face guilt and stigma. It has been recognized that self blame regarding the cause of a child’s disability is related to less positive parent-child relationships (Masood, Turner, & Baxter, 2007) and higher levels of depression among parents (Mickelson, Wroble, & Helgeson, 1999). Although the above studies discuss the

impact of self-blame on parents of children with other disabilities, the experience of guilt, shame and stigma for mothers of children with FASD may be different considering the blame inherent within the diagnostic process. More information is needed on the experience of shame for birth mothers of children with FASD and how that experience impacts their lives and the lives of their children. This section will critically review some of the current literature on guilt and shame and the effects of guilt and shame on individual's and family's emotional and mental health.

Guilt and shame are conceptualized as two separate and distinct emotions in academic literature. Guilt is experienced when an individual is concerned with his or her behaviours or actions which harmed another or were in violation of a moral standard (Dost & Yagmurlu, 2008; Nelissen & Zeelenberg, 2009; Schmader & Lickel, 2006). Guilt is seen to be an adaptive emotion which encourages pro-social behaviour and invokes actions which seek to repair damage (Dost & Yagmurlu, 2008; Nelissen & Zeelenberg, 2009; Schmader & Lickel, 2006). In contrast, shame is an emotion in which the individual targets his or her self as opposed to their actions; the behaviour is seen as part of a flaw in their own character (Dost & Yagmurlu, 2008; Schmader & Lickel, 2006; Silfver, 2007). Shame is thus seen as a more maladaptive emotion which is related to avoidance behaviours and withdrawal (Dost & Yagmurlu, 2008; Schmader & Lickel, 2006).

Guilt and shame are further distinguished in that guilt is a self-directed emotion, governed by internal morality, whereas shame is linked to actual or anticipated disapproval from others (Frich, Malterud, & Fugelli, 2007). Although shame is generally considered to be the more maladaptive of the two emotions, recent research has identified that there may be destructive elements related to guilt as well (Dost & Yagmurlu, 2008; Nelissen & Zeelenberg, 2009; Silfver, 2007). It has been suggested that there may be individual predispositions to feeling either shame or guilt (Schmader & Lickel, 2006). Considering the lack of research into shame and guilt as an experience for birth mothers of children with FASD, I will use both of the terms shame and guilt throughout this document. This recognizes that either emotion may be present for different women.

The consequences of guilt and shame in the lives of individuals experiencing them are varied. Since shame is considered the more maladaptive of the two emotions, some research states that shame, but not guilt is related to psychological problems (Dost & Yagmurlu, 2008). Shame has been linked to increased problems with alcohol and drug use, increased personal distress (Dost & Yagmurlu, 2008) and actions seeking to escape or strike back at the victim of

the action (Silfver, 2007). Despite the positive aspects of guilt in encouraging pro-social behaviour, it has been linked to depressive symptoms and psychopathological symptoms (Dost & Yagmurlu, 2008), anti-social tendencies and mental health issues (Silfver, 2007). One recent article regarding the impact of guilt found that if individuals are not able to engage in retributive actions towards the victim, they may engage in self-punishing behaviours, which the authors label as “the Dobby Effect” after a popular *Harry Potter* character (Nelissen & Zeelenberg, 2009). Since repairing the damage of actions is impossible for birth mothers of children with FASD, self-punishment may be a part of some women’s experiences.

Since both guilt and shame have been found to have possible negative consequences, it is suggested that the situational context, coping strategies and individual differences must be considered when evaluating the impact of guilt and shame (Silfver, 2007). Since these consequences of guilt and shame are contextual and varied, it is important to understand how guilt and shame impact the lives of birth mothers of children with FASD. If guilt and shame is acknowledged and supports and coping strategies are provided, perhaps the negative consequences for birth mothers can be reduced. A similar important aspect to understand in the lives of birth mothers of children with FASD is how experiences of blame and stigma impact the women’s lives. The next section will critically outline some of the available research on blame and stigma in relation to birth mothers of children with FASD.

Blame and Stigma

The public discourse related to substance abuse and pregnancy in Canada has been described as “blaming, judgemental and unsympathetic” (British Columbia Centre of Excellence for Women’s Health, 2007). All but one of the diagnoses under the FASD spectrum requires confirmation of maternal drinking during pregnancy (Chudley et al., 2005). Therefore, blame on the biological mother is an inherent part of the diagnostic process. Badry (2008) states, “The term FAS is culturally loaded, and it clearly infers that the birth mother is at fault for having caused damage to the fetus.” (p. 214). Although the research regarding risk factors and characteristics of birth mothers of children with FASD points to histories of poverty, trauma, abuse and violence (Astley et al., 2000b; May et al., 2005; May et al., 2008), the discourse around substance abuse and pregnancy places responsibility solely on the shoulders of the women themselves (A. Salmon, 2007). Substance abuse during pregnancy is widely seen as problems with individual behavioural choices rather than situated within the broader social

contexts of poverty, violence and racism (A. Salmon, 2007). This judgemental attitude has led to birth mothers of children with FASD left as “voiceless, victimized, dehumanized, disenfranchised and silenced” (Badry, 2008 p.196).

A variety of contexts have placed blame on birth mothers of children with FASD in our society, including academic articles (Toutain & Lejeune, 2008), the media (Eliason & Skinstad, 1995; Rutman, Callahan, Lundquist, Jackson & Barbara Field, 2000), institutions (Badry, 2008) and politicians (Szabo, 2000). Studies with adoptive and foster parents of children with FASD have found anger and blame towards the birth mother to be common experiences (Clement-Murphy, 2001; Gardner, 2000). This blame towards the birth mother is represented within a publication by Canadian Member of Parliament Paul Szabo (2000). Szabo presents the responsibility of the prevention of FASD as twofold: the responsibility of society to ensure awareness and education about the dangers of drinking during pregnancy, and the responsibility of the mother who “must choose to abstain from drinking to safeguard her unborn child” (Szabo, 2000, p. 112). Using rhetoric of individual choice and responsibility, Szabo represents substance use during pregnancy as a woman’s deliberate choice to “ignore the warnings” and drink during pregnancy (Szabo, 2000, p. 113).

The representation of alcohol use during pregnancy as an individual and conscious choice independent of social and environmental contexts has led to the defining of FASD as 100% preventable. This representation presents women as the sole “cause” of FASD, further blaming and stigmatizing them and their children. Tait (2003) argues that:

The claim that FAS is one-hundred percent preventable is grounded in a moral sentiment rather than in an awareness of the challenges and problems that mark the daily lives of women with substance abuse problems. Further, if consideration is given to the complexities of these women’s lives, including their substance abuse and pregnancies, and to the numerous gaps and barriers in service provision and support for the women and their children, the claim that FAS is entirely preventable serves more to blame and stigmatize women than to highlight a goal that is achievable (p. 8-9).

By framing the use of alcohol during pregnancy as an individual choice, and FASD as 100% preventable, society has “demonized” pregnant women who drink alcohol (Tait, 2003, p. 20).

This discourse regarding women and substance use has also led to prevention activities that focus simply on educating women and ask them to stop drinking during pregnancy (Baxter et. al 2004). By ignoring the fact that many women drink during pregnancy as a result of complex social and financial interactions, society simply asks women to “stop drinking.” This further marginalizes those women who are unable to stop using substances during pregnancy without support. When viewing one of these education/prevention posters, a birth mother of a child with FASD commented, “This poster, and all the other ones, imply that quitting drinking is simply a choice. Don't people think I would have quit if I could?” (Christie, n.d.)

This societal blame and stigma may negatively impact birth mothers in many ways. Two main factors identified in the literature are the danger that this stigma presents to the self-esteem of the mothers and to their ability to seek treatment. The idea that individuals often internalize others' views of themselves in their own self- representations was described as the “looking glass self” by classical sociologist Charles Cooley (1902, cited in Gamble & Yu, 2007). In a study of illicit drug use, Simmonds and Coomber (2009) found that the internalization of stigma by drug users reduced the effectiveness of prevention and harm reduction programs. Canadian substance abusing women cite self-image and self-esteem problems as barriers to seeking treatment (Poole & Isaac, 2001). The authors assert that “this response shows how pervasive negative stereotypes about mothers who use substances influence women's self-concept.” (Poole & Isaac, 2001, p. 14). The prevailing attitudes in society regarding substance use and pregnancy are likely to increase the marginalization of women, deter them from seeking the help that they need and contribute to further feelings of guilt and shame (Poole & Isaac, 2001).

Recent research from feminist perspectives has challenged the dominant belief that substance use during pregnancy is an individual choice that occurs independent of social and contextual problems. They suggest instead that women's actions must be considered in relation to others and the community and that the discourse around pregnancy and substance abuse must be considered in relation to social, political and environmental factors which influence women's substance use as well as the development of FASD (Badry, 2008; Marcellus, 2007; Schellenberg, 2007). Badry (2008) asserts that “the notion of self-restraint to prevent FAS is not plausible without addressing societal / cultural / gender issues around the individual and use of alcohol” (p. 214). The ignoring of contextual factors while blaming women for the problem of FASD is one reason that feminist theory is important to this study.

Feminist Research Practice

In beginning work on this research project the use of feminist theory made sense to me for several reasons. First, birth mothers of children with FASD are, by definition, only women. These women alone are blamed and shamed for the disabilities of their children. Secondly, I believe strongly in the importance of viewing the choices and actions of individuals within the social contexts in which they live, an important principle of feminism. As I began to read further into the research with birth mothers of children with FASD and with substance abusing mothers, I saw additional connections. The writings of Dorothy Badry (2008), Susan Boyd and Lenora Marcellus (2007) and Elizabeth Armstrong (1998, 2003) supported my opinion that the diagnosis of FASD was serving to further marginalize the most poor and stigmatized women in Canadian society. The prevention discourse in Canada focuses on controlling the behaviours and choices of women, rather than on the contextual and societal factors which lead to the abuse of alcohol by many women. The fact that most women who abuse substances do so for self-medication purposes after suffering abuses and mental health issues (Leischner, 2001) remains largely unrecognized. The focus on blaming the women means that the victimizations these women have suffered and the lives these women have led become “unworthy of attention” (Armstrong, 2003).

A further reason for the importance of feminist research practice in this context is the historical ignoring of the father’s impact in the development of FASD. Since the birth father’s drinking does not alone produce FASD, mainstream prevention research largely dismisses their role and focuses solely on the actions of the women. However, when using a feminist standpoint to examine this phenomenon, it is important to recognize that women’s actions do not occur in isolation from their social contexts (Marcellus, 2007). The birth mother’s relationship with the birth father was an important theme in “becoming” a birth mother of a child with FASD in the study by Badry (2008) in several ways. The birth father was the main person whom the mothers consumed alcohol with during their pregnancies and often expressed little concern about the mothers’ use of alcohol during pregnancy (Badry, 2008). The relationships described by the women were often characterized by violence and alcohol was often used as a method of coping and escape from the abuses the women suffered from their partners (Badry, 2008). Despite these relational factors, birth fathers are largely ignored in academic research regarding FASD (Badry, 2008).

In an analysis of the treatment of women in the debate on fetal rights, Katha Pollit discusses the charges that are laid against women in the United States regarding “duty of care” when they are found drinking during pregnancy (1998). She contrasts this with the fact that although one in twelve women are beaten during pregnancy, we do not know how many stillbirths, miscarriages and birth defects are caused by male violence. Pollit describes an example from Wyoming, U.S., in which a pregnant woman was charged for drinking during pregnancy when she presented at an emergency room for injuries inflicted by her husband. No charges were laid against her husband (Pollit, 1998). Although maternal stress has been found to be a factor in the extent of damage caused by alcohol use during pregnancy (Abel, 1998), little attention has been given to the impact of male partners’ behaviour on the outcome of the fetus. FASD remains a woman’s problem in the academic and mainstream literature.

This marginalization, blaming and silencing of women makes the use of feminist theory extremely important in this research context. By using a feminist standpoint, this research has strived to see and understand the world through the eyes of oppressed women, and apply that knowledge to social activism (Hesse-Biber & Leavy, 2007). A feminist standpoint will draw on women’s concrete experiences as a starting point to build knowledge which will be used to give light to larger social and economic issues and inequalities within our society (Hesse-Biber & Leavy, 2007). This research is thus not value-free, I entered this research with a specific agenda: to empower birth mothers of children with FASD, to break down stereotypes, increase understanding and to reduce blame, shame and stigma in the lives of birth mothers. Using a feminist standpoint allows me to value the voices of women who have been silenced and to work towards active change in Canadian society.

My goal for this study is not to continue the stereotype of birth mothers of children with FASD as victims, as bad mothers, or as women who are unable to care for their children. I would like to acknowledge birth mothers as powerful sources of information, resiliency and ability. In working towards that goal I will undertake feminist research practice, which takes great care in providing transparent accounts of the research process, and involving participants in the research (Comak, 1996). Feminist research emphasizes the importance of each woman’s voice and perspective (Saul, 2003). Reinharz (1992) articulates why feminist research is a good fit for the goals of this research, stating that feminist research commits to “making the invisible visible, bringing the margin to the center, rendering the trivial important, putting the spotlight on women

as competent actors, [and] understanding women as subjects in their own right” (p. 248). By using these ideals, I seek to empower my participants and collaborate with the women in creating new understanding of the meaning of being a birth mother of a child with FASD.

In order to ensure I am conducting feminist research, I have used several strategies which were outlined by Letherby (2003). She suggests that feminist researchers must be sure to pay attention to the significance of gender; to challenge objective knowledge; to value personal knowledge; to develop non-exploitive research relationships; and to value reflexivity and emotion as sources of insight (Letherby, 2003, p. 73). These values are further articulated throughout the next chapter which describes the methodology used to address an important gap in the literature: what are the experiences of birth mothers of children with FASD after the birth of their child?

CHAPTER 3

METHODOLOGY

This chapter will describe in detail how I carried out this research study, including a discussion of the methodology used, the population, sampling and recruitment issues, the approaches to data generation and analysis, as well as considerations of rigor and credibility.

Research Question

Research questions in phenomenological inquiry are those which question the nature of a particular experience for a group of individuals (van Manen, 1990). Questions are designed to keep possibilities open for what will be discovered during the research process (van Manen, 1990). I came into this research with an interest in guilt and stigma in the lives of women who have given birth to a child with FASD. However, being unsure of the true experiences of birth mothers of children with FASD, and having a desire to remain open to possibilities in a phenomenological context, I created a research question which was open to any experiences birth mothers of children with FASD may have. The research question for this project was thus to explore the essence of the experience of birth mothers of children with Fetal Alcohol Spectrum Disorder since the birth of their child.

Relevance of Qualitative Research

Considering the dearth of research available on the experiences of birth mothers of children with FASD, qualitative research is necessary in order to understand women's experiences in detail. Qualitative research is based on a series of assumptions regarding the nature of human experience which are relevant in this research context. Qualitative research usually follows a constructivist paradigm, which is a position that assumes there are multiple, equally valid realities (Ponterotto, 2005). This reality is constructed in the mind of the individual. Qualitative inquiry results in ideographic and emic understandings of a phenomenon (Ponterotto, 2005). It is with these goals in mind that I chose qualitative methods as an appropriate method of inquiry to describe the experiences of birth mothers of children with FASD. More understanding of the depth of these women's experiences is needed to complement the limited quantitative data that is available. Qualitative research will allow the stories of the birth mothers to be told in an in-depth and contextual manner.

A further reason for the choice of qualitative inquiry is my own assumptions about the nature of reality and the use of knowledge. Personally, I see the world through a constructivist,

as well as an advocacy/participatory lens. I believe that there are multiple ways of knowing the world and experiencing a phenomenon, and that these ways of knowing depend largely upon the social and cultural contexts in which one lives. All experiences are interpreted through the perspective of the individual experiencing it. This respect of individual knowledge and critical view of objective knowledge are consistent with the beliefs of feminist theory outlined in the previous section (Letherby, 2003). Furthermore, I also believe in the importance of participation between the researcher and the participant in the generation of data and the importance of using knowledge to advocate for change. These assumptions about the world and knowledge have guided me to qualitative research, feminist theory (which advocates for change and participation) and more specifically, to phenomenology as a methodology.

Phenomenology

It has been asserted that phenomenological studies must begin with a discussion of the philosophical roots of phenomenology (Creswell, 2007), I will therefore begin by discussing some of the basic assumptions of phenomenological thought and how they relate to modern phenomenological research. Phenomenology involves the study of phenomenon as they appear to individuals when they lay aside the customary understanding of that phenomenon (Gall et al., 2007). Phenomenological research has its foundations in the philosophical work of Edmund Husserl (Creswell, 2007; Gall et al., 2007; Langdrige, 2007; Merriam, 2002). Husserl believed that knowledge was reached through the self's experience of phenomenon as it appears in consciousness (Gall et. al, 2007). He stressed a "return to the things themselves" in the creation of knowledge (Langdrige, 2007, p. 4). This return to the things themselves is expressed in phenomenological research through the study of lived experiences and a focus on perceptions of those experiences (Langdrige, 2007).

Husserl formed many concepts regarding knowledge and how humans interact with the world which are the basis of modern phenomenology. One such concept is "intentionality" which is the underlying assumption behind the focus of lived experience and perception in phenomenology. Intentionality is the idea that whenever we are conscious, it is to be conscious of something; there is always an object of consciousness (Langdrige, 2007). Consciousness is therefore not directed inwards on our own thought, but turned out on to the world, consciousness intentionally relates to objects in the world. This concept leads to the phenomenological assumption that

research should focus not on cognition, but rather on the interaction between internal perception and the experience of our world (Langdridge, 2007).

A second concept which is of great importance to phenomenological research is the relationship between what Husserl labelled “noema” (what is experienced) and “noesis” (the way it is experienced). Husserl asserts that the relationship between noema and noesis is universal and inextricable; what is experienced is always influenced by the way it is experienced. This concept leads to the assumption in modern phenomenological thought that an individual’s perceptions of an experience will differ according to the context in which that experience occurred (Langdridge, 2007). This relationship between the experience and the context in which it is experienced was a great pull for me in the choice of phenomenology. In this research context with birth mothers of children with FASD, it is important for researchers and policy makers to learn from the experiences of women who have lived through the experience and interpreted that experience from their own cultural and situational lens. It is through this contextual information that a greater understanding of the experiences of birth mothers can be gained.

A third main concept which was created by Husserl is the idea of epoché, or bracketing. This concept is central to much phenomenological thought, and is the idea that a phenomenon can be understood through the perspective of the individuals being studied, if the researcher first engages in a process of recognizing their own biases and setting them aside (Gall et al., 2007; Langdridge, 2007). This concept will be discussed further in the data generation section to follow.

Similarly, the concept of reflexivity of the researcher is another important assumption in phenomenology. Knowledge is thought to be a co-construction between the researcher and participant, reflecting the choices of the researcher as much as the information given by the participant (Langdridge, 2007). The researcher is seen as a partner with the participants in the creation of data (Langdridge, 2007). In a qualitative, and specifically a phenomenological study, “the researcher is the instrument” (Richards & Morse, 2007) in data generation, analysis and representation. The researcher is thus an active participant in the research, and must continually evaluate their own biases, assumptions and choices throughout the research process. It has been noted that researcher reflexivity is extremely important in research contexts in which the researcher is an outsider studying a vulnerable population. There is a danger of perpetuating stereotypes or misrepresenting information in those cases (Langdridge, 2007). Because this

research context is one in which I am an outsider studying a vulnerable population, I attempted to engage in reflexivity throughout the process, not only at the outset. Throughout this document I disclose my agency in the research, and recognize the importance of my own actions within the study. Taking into consideration the impact that my own actions and presuppositions have on this research, I have attempted to make my assumptions transparent throughout the process. This was partially assured through a process of journaling which I will discuss in greater detail in the data generation section of this document.

A final concept of Husserlian thought which influenced this research is the idea of essence. Husserl believed that it was possible to ascertain the essence of an experience through identifying the universal structure underlying an experience. This is achieved through the recognition that any individual experience is not a piece of information, but rather an expression of the essence itself (Langdridge, 2007). This focus on the essence of an experience is still a focus of modern phenomenological research, as analysis of data seeks to discover common themes between individuals who have experienced the phenomenon (Akerlind, 2005). Phenomenological analysis seeks a composite description of the essence of the phenomenon through a focus on these common themes and experiences across participants (Creswell, 2007). Thus the focus is not on the experiences of each individual being studied, but rather the essence of the experience of the phenomenon.

Hermeneutic Phenomenology

Phenomenological research is based in the work of Husserl, but has taken many different forms throughout history. Phenomenology is best described as a family of approaches, rather than one approach in itself (Langdridge, 2007). Some phenomenological researchers follow closely the ideas of Husserl, seeking to truly bracket off all preconceptions about a phenomenon and offer a description of the essence of that phenomenon. These researchers are descriptive or transcendental phenomenologists (Creswell, 2007; Langdridge, 2007). Alternatively, hermeneutic or interpretive phenomenologists seek to interpret the lived experiences of participants, focusing less on description (Creswell, 2007; Langdridge, 2007). Interpretive phenomenology places less faith in the idea that assumptions can be completely put aside, asserting instead that the production of meaning derives from both the interviewer and the interviewee (Langdridge, 2007; van Manen, 1990). This research has followed an interpretive form of phenomenology, drawing largely from the works of Max van Manen, (1990) because of

my own similar assumptions regarding the importance of going beyond simple description to a more interpretive understanding of the phenomenon and the inability of the researcher to truly bracket their own assumptions. Also, it has been asserted that the use of hermeneutic phenomenology provides greater understanding than the use of empirical methods based strictly on the ideas of Husserl (Tobin & Begley, 2008).

In using hermeneutic phenomenology, the aim of this research was to come to an interpretive understanding of the experience of birth mothers of children with FASD. The research followed the general guide outlined by van Manen (1990). This guide includes six general basic steps in carrying out a hermeneutic phenomenological study. The first is choosing a phenomenon of personal interest; secondly the researcher investigates the experience as it is lived, not as it is conceptualized. Third, the researcher reflects on the essential themes of the phenomenon. Fourth, the researcher writes a description of the phenomenon through the art of writing and rewriting. Fifth, the research must maintain a strong orientation to the phenomenon. And finally, the interpretation of the phenomenon must balance the parts and the whole (Langdridge, 2007; Creswell, 2007; van Manen, 1990). This process started through choosing a topic that is of personal interest to me. How the remaining steps were followed will be described throughout this methodology section; you will find these general steps within the headings of this chapter.

Relevance of Phenomenology

Research with birth mothers of children with FASD is an area in which much work is needed. As of 2008, only one study has been published which dealt specifically with the subjective experiences of birth mothers of children with FASD (J. Salmon, 2008). This creates little knowledge on which to develop programming and guide further research. Phenomenological research has been identified the best approach on which to develop practice or develop deeper understanding of a phenomenon (Creswell, 2007). The research question used here is open ended, seeking understanding, not causation, which is also well-suited to phenomenological research (Langdridge, 2007). Furthermore, phenomenological research has been described as compatible with the study of psychological phenomena which are important to specific groups of people, in this case the phenomenon of guilt in birth mothers of children with FASD (Merriam, 2002). Finally, phenomenological research is to begin with a research area which is of personal and social significance (Gall et al, 2007), both of which are of particular importance as this topic is close to my work experience and a growing societal concern.

There are many stereotypes, stigmas and blame associated with this research question, which makes phenomenology a particularly pertinent research methodology to select. It is asserted that when phenomenological research is done well, the result is that the reader will come away feeling that they better understand what it would be like to live through that particular experience (Creswell, 2007) It is my hope that a phenomenological study of the birth mothers of children with FASD will assist in fostering understanding and breaking down stereotypes.

Sampling and Recruitment

The population of interest for this study was originally defined as birth mothers of children diagnosed with FASD in Saskatchewan, who are currently involved in the parenting of that child and who are willing and able to tell their story. There are four participation criteria contained within that statement. First, the study focused only on birth mothers, excluding adoptive or foster parents or birth fathers. The rationale behind choosing that specific population relates directly to the research context of guilt and stigma. Birth mothers of children with FASD are blamed within the process of diagnosis and by the community, thus the experiences of these mothers are of specific concern. Second, the original criterion was that the child must have had a diagnosis of FASD; I believed this was important in the understanding of the experiences of the mothers throughout the diagnostic process which places blame on their shoulders. However, as participant recruitment issues arose, this criterion was removed. Participants who stated that they drank during pregnancy and that they considered themselves to be birth mothers of children with FASD were included in the study.

The third inclusion criterion, that the mother must be involved in the parenting of the child with FASD, was also important in terms of the research question. I was interested in how a birth mother experiences parenting and the constant interaction with her child's disability within the context of guilt and stigma. It was also important within the context of hermeneutic phenomenology that the experience is researched as it is lived, not as it is reflected upon (van Manen, 1990). The final inclusion criterion, that the women are willing and able to tell their stories, was important methodologically, practically and ethically. Methodologically, a hermeneutic phenomenological study is represented as a textural description of the essence of a phenomenon (van Manen, 1990); therefore detailed descriptions of experiences are needed to create a linguistic interpretation of the phenomenon. Practically, the women must be able to talk about their stories in detail for the interpretation to occur; and ethically, they must also be at a

point in their journey where they are able to tell their story without producing further harm. Finally, also for ethical reasons, I required the participants to be at least eighteen years of age. This ensured that they were able to provide informed consent for participation.

The original goal was to use purposive sampling to gather two to four women who fit the criteria for the study. Relatively small samples are generally used in phenomenology due to the time consuming nature of the analytic process (Langdridge, 2007). Purposive sampling is common in phenomenological research (Langdridge, 2007), as it is necessary to gather participants who have experienced the specific phenomenon to be studied. I also hoped to engage in maximum variation sampling in order to generate understanding from the perspective of individuals from a variety of different backgrounds (Langdridge, 2007). This would allow the exploration of what aspects of the phenomenon are variable and invariable across perception (Langdridge, 2007). In this research context, maximum variation sampling would result in a group of participants who are all birth mothers of children with FASD; however they would differ in terms of demographic information that may create differences in how they have experienced the phenomenon. These demographic differences could include ethnicity, age, geographic location, socio-economic status or marital status.

In order to locate women who fit the criteria for the study, a letter was first sent out to the members of the FASD Support Network of Saskatchewan in June 2009. The FASD Support Network of Saskatchewan is a parent-lead and community based organization which provides advocacy and support to individuals with FASD and their families (FASD Support Network of Saskatchewan, 2010). The FASD Support Network has a contact list across Saskatchewan, Canada and internationally who are interested in information regarding FASD. This contact list includes many birth mothers of children with FASD.

The letter of invitation was sent along with a brief introduction from the FASD Support Network of Saskatchewan. The letter included the purpose and nature of the study, what to expect from the interview process, the interview setting, the number of interviews needed, the type of information that the interview will cover, possible benefits and risks of participation and contact information. This original letter for participant recruitment is included with this document as Appendix A. My hope was that I would receive enough interest in the study through the recruitment letters to have two to four participants. However, the summer of 2009 passed

without any contact from potential participants. It became clear that changes were needed to my recruitment protocol in order to reach the women that I was seeking.

An amendment to my recruitment procedures was sent to the University of Saskatchewan Research Ethics Board in September 2009. That amendment included small revisions to the recruitment poster (see Appendix B); and approval to include recruitment materials at an FASD conference in Saskatoon. When no participants were identified by October 2009, I decided that more efforts were needed to contact this hard-to-reach population. Another ethical amendment was completed for the following changes: the broadening of the research area to all of Saskatchewan; a new recruitment poster (see Appendix C); a \$50 honorarium per interview for each participant; the use of snowball sampling so that organizations could phone women who may be interested; recruitment at a parent retreat for parents of children with FASD; and the ability for me to make initial contact to women who have expressed their interest to people working at support agencies throughout the province. I believed that this final criterion was necessary since I was getting reports from several agency members that there were women who were interested in participating, but following through on phoning was difficult for them. Scripts were created for the snowball sampling and for the initial contact by me to the participants, to ensure that the process was not coercive. These scripts are in Appendix D and E.

Following the final changes to recruitment, letters were sent across the province by email; posted at agencies throughout the province; and given to parents at the parent retreat. Two women contacted me at this point regarding participation. These women fit the criteria, except for the criterion regarding diagnosis. Both women had used alcohol during pregnancy and had children with difficulties, but one had no diagnosis, and the other's child was in the process of diagnosis. I decided, in consultation with my supervisor, that the women should be allowed to participate without the formal diagnosis for their child. Many people with FASD go undiagnosed and there is currently a long waiting list in most areas of Saskatchewan to access diagnosis. Finally, two further women were accessed after a phone call from an employee at the FASD Support Network of Saskatchewan. The woman who was called agreed for me to call her about participating. She agreed to participate and also gave me her friend's phone number, telling me that her friend would also like to participate. Both women joined the study.

The use of the FASD Support Network and other support organizations to recruit participants may have introduced some level of sampling bias into the research. There may be

some differences between the women who access such supports and women who have not yet accessed supports for themselves or their children. This may be a limitation to the study. A further sampling bias may occur within the inclusion criteria that the woman must be parenting their child. This study may not be reaching the most stigmatized of women, those who have not yet accessed supports, diagnosis and who have not been able to parent their children. Although this is a limitation, these criteria were necessary in order to learn from women who have accessed services and have been able to mother their children. Four women were recruited to participate, and the research thus moved along to the process of data generation.

Data Generation: “Investigating the Experience as it is Lived”

Since the “researcher is the instrument” in data generation (Richards & Morse, 2007), this section will begin with my processes of reflexivity throughout the research, followed by a description of the interviews that were held with each woman.

Reflexive Research

A main aspect of the data collection and analysis process of phenomenology is the concept of epoché, which was created by Husserl, the founder of phenomenological thought (Langdridge, 2007). Epoché is the process by which we attempt to set aside our presuppositions or ideas about the phenomenon which we are researching (Langdridge, 2007) and has been commonly labelled as bracketing. There is much debate in modern phenomenological research as to whether or not this can truly be achieved (Ashworth & Chung, 2006 ; Langdridge, 2007). Many researchers believe that you should attempt to achieve epoché but you will never reach a true “God’s eye view” of a phenomenon (Langdridge, 2007, 18). That is the position that I took within this research project. An attempt was made throughout the process to recognize and set aside my own biases in order to understand the perceptions of the participants and discover the essence of the experience. However, I also recognized that I would not truly achieve the setting aside of these biases; my own views and perceptions have influenced the research process. This is both acceptable and expected in interpretive forms of phenomenology, in which it is believed that the knowledge created in research is a combination of the perspectives of the participants and the researcher (Langdridge, 2007).

My first attempt at bracketing and laying aside my presuppositions was in the writing of the forward to this document. In that section, I outlined my own personal interest in this particular topic area, as well as some of the biases with which I entered the research. I have attempted

throughout this research to put aside these personal experiences, to allow the experiences of the women to be interviewed to be viewed with as little bias as possible. In a further attempt to not allow these assumptions to influence the research process, I outlined my research question without naming guilt or stigma as main areas of study. This was also reflected in the interview questions, which focused on the experiences of the women, allowing them to tell their own stories, without questions which name guilt and stigma. This assisted me in coming to a greater understanding of the essence of the experience, with less impact of my own biases.

A further attempt to track my personal assumptions throughout the research process was carried out through the process of journaling. Gadamer (cited in Langdridge, 2007) suggested that phenomenological researchers use a study diary to keep track of their own emotional responses and what they might mean in terms of understanding the phenomenon. Journaling assisted in identifying my own biases throughout the process, and how those biases influenced the research process. I used journaling increasingly as the process continued, especially as I began to read the participants' stories. It was during that time that I engaged in the most careful reflection, hoping to reduce the bias in my interpretation of the women's' stories. Data in qualitative research is created through both the research participants and the researcher; the choices I made throughout the research affected the data that generated (Richards & Morse, 2007). Journaling has assisted me in keeping track of my own role in the creating of data and has increased the reliability of the study by providing an audit trail describing how I arrived at the results (Merriam, 2002).

Interviews: “Maintaining a Strong Orientation to the Phenomenon.”

The most commonly used method of data collection in phenomenological research is the interview (Creswell, Hanson, Clark, & Morales, 2007; Langdridge, 2007; Merriam, 2002). Interviews were chosen in this research context as the best method to gain insight into the lived experience of birth mothers of children with FASD. Since this topic is not extensively researched and birth mothers of children with FASD have been historically marginalized, I believe that hearing stories from the women themselves is the most relevant form of data generation. This has allowed me to interpret and understand the experience of being a birth mother of a child with FASD with data from the voices of the women themselves. Interviews with the women who are experiencing this phenomenon allowed me to “maintain a strong orientation to the phenomenon” and to “borrow” the women's reflections on their experiences, in order to come to a better

understanding of the essence of that experience (van Manen, 1990). The use of personal interviews is also in line with the feminist assumptions that I strived for in this research: the valuing of personal experiences and emotion as a source of insight (Letherby, 2003).

Each woman participated in three separate interviews on three separate occasions. This allowed for the developing of trust and the building of rapport. There are many sensitive topics in this research area, and allowing for more than one interview permitted me to save more emotional questions for later interviews. I was also able to engage in what van Manen (1990) describes as a hermeneutic interview, in which the reflection on data and the generating of data happen simultaneously. After the review of the first interview transcripts, subsequent interviews gave the opportunity for me to clarify points with the interviewees and engage in discussion about the transcripts. In doing so, the creation of knowledge became a collaborative process with myself and the participants (van Manen, 1990). The use of three interviews was also chosen based on the feminist belief in non-exploitive research relationships (Letherby, 2003); I was able to be respectful of the women's experiences by allowing them further time to tell their stories and the opportunity to check my interpretations of their stories.

There was a specific purpose for each of the three interviews. The first interview was used to begin the process of data generation, asking the women about their journey as a birth mother of a child with FASD. The first interview was also used as a method of rapport building, of learning more about each woman and allowed each woman to tell her story in a way that she was comfortable. I began each interview by asking the women to tell me a bit about themselves. I used very few prompts for most of the women, depending on each of their personalities and comfort level. Later on in the interview the overarching question was read to each woman in order to focus the interview on FASD and their experiences as a birth mother.

Following that first interview, I engaged in the process of transcription to help in the decisions of what questions to create for the second interview. In reading through the first interviews, I created questions for the second interviews that were individual to each participant, based on areas of the first interview which I wanted the participant to expand upon. The second interview was an opportunity to gather more in-depth and detailed accounts from the women. There were often specific stories that were mentioned in the first interviews that I asked the women more detail about during the second interview. There were also several opportunities for clarification of points made in the first interview. Due to my inexperience as a researcher, there

were many times during the process of transcribing the first interview where I wished I had clarified a point or asked for more information. Returning to the women for second interviews provided a second chance for those missed opportunities. It also provided much more rich detail about the women's experiences and a chance to ask questions about the difficult emotional journeys each woman had traveled in being a birth mother of a child with FASD.

After the completion of the first two interviews with all participants, I searched for themes within the data generated up to that point. The specific processes which I engaged in are discussed in detail in the data analysis section to follow. The third interview was a hermeneutic interview; tentative themes were brought to each participant to discuss how each woman identified with the themes. This interview allowed me to collaborate in more detail with the participants in the creation of knowledge, which follows the ideas of van Manen (1990), as well as the principles of participation and collaboration important in feminist research. The women were each presented the tentative themes that had been generated up to that point in time and were given the opportunity to make any changes to their story and to offer any additional information or interpretations to assist in my understanding of the phenomenon. Table 3.1 outlines the purpose of each interview.

Table 3-1. Description of Interview Purposes

Interview	Purpose of Interview
Interview #1: Rapport building	This initial interview included learning more about the participant, rapport building and the overarching question. Few prompts and leads were used.
Interview #2: In-depth data generation	Gathered more in-depth information about the women's stories. Areas to probe were selected from the first transcript.
Interview #3: Hermeneutic Interview	Initial tentative themes from the participant data were brought to each participant for discussion. Transcripts from the first two interviews were signed off on at this point.

The interviews followed a semi-structured format; I created a general guide including pre-formed questions to be asked, but flexibility was used during the interviews in order to gather information on each participant's specific experience of the phenomenon (Gall, 2007). The semi-structured interview was chosen over the unstructured interview following the recommendations of van Manen (1990), who states that unstructured interviews often result in too much material, leading questions from the researcher, or material that lacks sufficient concreteness (van Manen, 1990). The use of a semi-structured format allowed a specific focus on the topic at hand, while at the same time allowing for flexibility based on the responses and experiences of participants. I attempted to ask questions in an open-ended manner in order to gather as much of the participants' own interpretations of experiences as possible, and to avoid the influence of my own bias. Each interview varied in length, dependent on the abilities and expectations of each participant, and ranged between 40 minutes and 1 hour 56 minutes. The interviews were digitally recorded, with the permission of each participant.

The interview questions were designed to elicit the full experience of a lived phenomenon for each individual (van Manen, 1990). The interview guide consisted of an overarching question which was asked to each participant, and a series of prompts which were used as necessary. The overarching question which was used was to "Please tell me about your experiences as a birth mother of a child with FASD since your pregnancy. I would like to know how FASD has impacted all areas of your life." Further prompts were used depending on the responses of the participant. Individual prompts specific to each woman's story were created before the second interview. The interview guide is outlined in Appendix F.

Data Analysis: "Balancing the Parts and the Whole."

This section will present an outline of how I approached the analysis of data for this study; including the transcription processes and thematic analysis. Before outlining the specific processes, I would like to point out that although the process of data generation and analysis are presented in this document in a linear fashion, that is not a reflection of how the process occurred. In a hermeneutic phenomenological study, analysis and data generation occur simultaneously (van Manen, 1990). Each interview was transcribed before subsequent interviews, allowing for ongoing analysis and the reflection on themes throughout the data generation process.

Transcription

The first step in data analysis was transcription. Since a thematic (but not conversational) analysis was used, a verbatim transcription was required, but without the symbolizing of all vocal activities (Rothe, 2000). This “denaturalized transcription” is the best method to study meanings and perceptions created and shared during a conversation (Oliver, Serovich & Mason, 2005). Denaturalized transcription is useful in analyses which seek an emic perspective and a description of participant perceptions (Oliver et al., 2005). I carried out the transcription process personally in order to begin the analysis and remain close to the data. After the completion of transcription and the first two interviews, participants were given the option of receiving a copy of the transcripts to review before the third interview. All four women chose to have the transcripts mailed to their home. The transcripts were sent with tracking numbers and signed upon delivery in order to reduce the possibility of losing confidential information. The third interview, or hermeneutic interview, was digitally recorded, but only the sections of the interview in which the participants offered new information about their experiences were transcribed.

Having the participants read through the transcripts increased the credibility of the study as the participants were able to confirm the accuracy of the data (Gall et al., 2007). It also gave the participants the opportunity to change or retract any statements they did not want included or that may jeopardize their privacy. Furthermore, if participants had extra pieces of information that they would like to add, they would have the opportunity to do so. None of the participants chose to change any aspects of their original transcripts and all signed a transcript release form during the third interview. This form is included in Appendix G.

Thematic Analysis: “Reflecting on the Essential Themes of the Phenomenon.”

The aim of data analysis in phenomenology is to transform the data into a textual description of the essence of a phenomenon (Richards & Morse, 2007). Through the process of making themes, I attempted to determine the structures that make up a particular experience (van Manen, 1990). The purpose of a thematic phenomenological analysis is not to describe the specifics of each individual’s account, but rather to attempt to unearth something meaningful from all of the accounts (van Manen, 1990). This process has been described as the “search for the universal (essence) in the particular (individual situation).” (van Manen, 1990, cited in Langdridge, 2007). In this research context, the aim of a thematic analysis was to unearth

themes from the women's stories which represent the meaning of the experience of being a birth mother of a child with FASD.

Going beyond this description, hermeneutic phenomenology seeks not only to describe the essence of a phenomenon, but also to make an interpretation of the meaning of experiences (Creswell et al., 2007). Themes in phenomenological research represent the experience of meaning. They are however, a reduction of meaning because they reduce the greater experience into a simple notion (van Manen, 1990). Each theme that was discovered represents a piece of the story, one "fastener" around which the description is generated (van Manen, 1990).

Thematic data analysis in phenomenology is a process of reading, reflection and writing and rewriting (van Manen, 1990). There are less rules and steps in hermeneutic phenomenology than in other forms of phenomenology; this is to prevent any foreclosure on ideas and to increase creativity in the research process (Langdridge, 2007). There are, however, several strategies in creating themes which were outlined by van Manen (1990), which were used as a guide in conducting the analysis. These general strategies include wholistic, selective and detailed theming.

The plan for data analysis was to use these strategies of a wholistic approach, a selective approach and a detailed or line by line approach to discover themes and to balance the parts and the whole (van Manen, 1990). The selective approach came most naturally to me as I read through the data. Using the selective or highlighting approach, I read and re-read the data searching for selective sentences that seem thematic and were particularly revealing about the phenomenon (van Manen, 1990). This seemed natural to me as I was already doing this as I transcribed the data, searching for common themes or phrases that seemed to tell me something important about being a birth mother of a child with FASD. Using this selective approach I pulled out phrases that seemed important and began grouping them into categories based on their meaning. Four main themes began to become apparent to me, along with several other categories that I wasn't quite sure of where they would fit or what they told me about the experience. The clarification of these categories was further delineated through the process of writing and rewriting discussed below.

Secondly, I re-read the data using the wholistic approach, examining the data for phrases which captured the significance of the text as a whole. Van Manen warns that this approach requires some judgement and subjectivity, as various interpretations of the text are likely to be

available (van Manen, 1990). I noticed that immediately and had difficulty conceptualizing how to use this wholistic theme-ing, since it seemed to me that there were too many layers of meaning to be reduced to a single wholistic statement. I therefore adapted this strategy to something that made sense for me by searching for a wholistic statement from each woman's story. Although the women's stories had similar themes running throughout, each woman added a specific important individual piece to the overall knowledge created by the research. In searching for a wholistic statement from each woman, I searched for a statement in their own words which clarified the most important piece of learning that I took from each individual story. I was able to further clarify the themes I had created using the wholistic approach, ensuring that each important piece of information was included within the themes, and also clarifying how these themes were connected to the other women's stories and the overall experience of being a birth mother of a child with FASD. These wholistic statements from the women's own words are contained within the description of each woman's story in the following chapter.

Finally, in the detailed, line-by-line analysis I analysed each sentence in the selections that I had earlier removed, asking "What does this reveal about the phenomenon?" (van Manen, 1990). By analysing data in this manner through repeated analysis of parts and whole, layers of meaning within the data are uncovered (Langdridge, 2007). The process of looking at each sentence or group of sentences was tedious, but worth-while. As I engaged in this process I began to uncover deeper meanings in the women's words, and notice further connections that hadn't been apparent during the first several readings of the text.

Following the detailed analysis I returned to the original transcripts to read through them another time using the selective strategy. This ensured that there weren't any important sections or phrases which told me something about the phenomenon which I hadn't highlighted and analysed during the first period of selective theme-ing.

As I delved further into the data I began to contemplate van Manen's four essential lifeworlds which all lived experience is centred around: lived space, lived body, lived time and lived human relation (van Manen, 1990). By categorizing human experience into these four overlapping areas, I began to think further about what the women's stories told me about this human experience, and how it is related to different areas of their lives. By thinking in this manner I began to see how the themes which emerged from the data were interconnected in many ways, and how this experience was also connected to other areas of the women's lives. Being a birth

mother of a child with FASD seemed to cross the boundaries of all four of these lifeworlds. I did not use van Manen's lifeworlds in my final representation of the data, but I began to integrate the ideas of lifeworlds into my analysis, which I hope helped deepen my understanding of the phenomenon and the ability to describe the phenomenon to my readers.

The balancing of the three approaches (selective, wholistic and detailed) takes into account the phenomenological rule of horizontalization; all details in the data are to have equal value, there are no hierarchies of meaning at this stage in the analysis (Langdridge, 2007). It is suggested that the use of these different approaches to searching for themes reduces the "likelihood of idiosyncratic interpretations which go beyond the data" (Langdridge, 2007). Throughout this process of creating themes, I attempted to distinguish between incidental and essential themes, by searching for themes that were unique to being a birth mother of a child with FASD and comparing these experiences to other similar experiences, such as being a mother who struggles with substance use or being a caregiver of a child with FASD. This allowed me to establish what is unique to the experience of being a birth mother of a child with FASD (van Manen, 1990). The distinction of essential themes allows a greater interpretation and the development of elaborations of the lived meaning of this phenomenon (van Manen, 1990).

Data Representation: "The Art of Writing and Rewriting."

The "art of writing and rewriting" is van Manen's (1990) fourth step in his guide of carrying out a hermeneutic phenomenological study. Writing and rewriting was used as a method of reflection and analysis to gain insight into this phenomenon. The process of writing is fused to the process of analysis within hermeneutic phenomenology; van Manen (1990) states "writing is our method". Like the process of data analysis and data generation; the analysis and representation of data were not a linear process in this research, rather they were intrinsically connected and circular. The process of writing and rewriting as a method of deeper analysis and interpretation was another personal draw for me to hermeneutic phenomenology. I value the process of writing as a method of clarifying ideas and developing understanding; it is a strategy which I have already developed over time, so it made sense for me as a method of analysis.

Writing thus occurred throughout this project, rather than at the end of analysis. I began to describe the themes in writing as soon as they began to develop within the first "stage" of analysis. This process of writing assisted me in clarifying the meaning of the themes and in

discovering connections among the themes and new ways of thinking about the data. As themes became clearer throughout the analysis, I would rewrite descriptions and interpretations.

Data representations in hermeneutic phenomenology are similar to a general qualitative inquiry format, although flexibility and creativity are allowed (Langdridge, 2007). The data is represented in a textural description of the essence of the phenomenon in the following chapter, and excerpts from the participants own words are used to highlight key themes and provide concrete examples. Van Manen (1990) points out that using “anecdotes” or excerpts from the participants, provides a concrete counterweight to abstract theoretical writing and shows the interconnection of life and theory. The excerpts used in the final representation were the participants exact words from the transcripts of their interviews, however speech patterns such as “um” and “you know” were removed for greater clarity. The goal of the data representation was to have readers experience the “phenomenological nod” (van Manen, 1990), or come to a greater understanding of what it would be like to experience this particular phenomenon. This will hopefully add to the body of knowledge regarding birth mothers of children with FASD, help reduce societal stigma and inform effective programming.

Rigor and Credibility

Numerous different ways of measuring rigor and credibility in qualitative studies have been developed (Anastas, 2004; Creswell, 2002). This study followed the procedural criteria outlined by Creswell (2002), which emphasize the importance of rigor in the procedures of the study. Since the researcher is the instrument in a qualitative inquiry (Richards & Morse, 2007), the importance of transparency in the procedures which were taken to arrive at conclusions within the study are of utmost importance to quality. The procedural criteria for measuring quality include eight dimensions (Creswell, 2002), which will each be discussed in more detail in terms of how they were aspired to in this research context.

The first dimension of procedural quality is the employment of rigorous data collection methods, including the use of multiple sources and extensive data (Creswell, 2002). Although this study used interviews as the sole method of data collection, data was generated through three interviews with four different women from very different backgrounds, allowing for extensive information and differing viewpoints. The second characteristic is that the study is consistent with the philosophical assumptions of qualitative inquiry (Creswell, 2002), including an emergent design, multiple perspectives, the researcher as an instrument in data collection and the

focus on participants' viewpoints. I believe that all of these assumptions have been discussed throughout this chapter in various aspects, such as emergent interview questions, a focus on the perspectives and voices of a variety of women and my own role in the research. The third criteria involves the use of a specific qualitative tradition (Creswell, 2002), in this case hermeneutic phenomenology has been anchored to as a method of inquiry. Fourth, the study should have a single focus of inquiry, rather than a comparison or relationship quantitative design (Creswell, 2002). In this case the focus is on the experience of birth mothers of children with FASD.

The last four criteria were considered throughout the study. These include a persuasive style of writing which leaves the reader with a feeling of "being there" and a narrative which engages the reader and contains believable and realistic information (Creswell, 2002). In my writing and representation of the data I have aimed for what van Manen (1990) has labelled as the phenomenological nod, where the reader finishes reading with a better understanding of what it would be like to experience the phenomenon. Multiple levels of analysis should be used to demonstrate the complexity of the analysis (Creswell, 2002); this was attempted through using the hermeneutic phenomenology strategies of wholistic, selective and detailed theme-ing (van Manen, 1990). Finally, the study should include strategies to confirm the accuracy of findings (Creswell, 2002). I attempted this in two ways, first in completing member checking by having participants sign off on transcripts to confirm accuracy (Gall et al., 2007), as described in the transcription section of this document. I also created an audit trail, which details the methods of data generation, analysis and reduction (Gall et al., 2007) through the process of journaling as described in the data generation section.

Ethical Considerations

Ethical considerations for this research, including informed consent, privacy, confidentiality, storage of data, participant recruitment issues, conflict of interest and dissemination of results are outlined in detail in Appendix H. This appendix is the application for ethical approval from the University of Saskatchewan Behavioural Research Ethics Board. The approval from the Ethics Board is included in Appendix I, and the approval for each of the amendments to recruitment procedures are included in Appendices J and K.

Informed consent was confirmed from each participant before the first interview through the signing of a consent form which outlined participation requirements and the right to withdraw at

any time. The consent form which each participant signed prior to participation in the study is included in Appendix L. Verbal consent was reconfirmed before each subsequent interview.

The privacy and confidentiality of participants was protected in several ways. First, participants' names and identifying information are not included in the write up of the final document. Second, participants were given the opportunity to review their transcripts and omit any information which may identify them. The transcripts were mailed to the participants following the second interview. In order to ensure privacy was maintained, the transcripts were sent by registered mail so they could be tracked and a signature was required upon delivery. The transcripts were then discussed with the women during the third interview where they had the opportunity to remove any identifying information. Third, all documents were stored in a locked cabinet throughout the research process and documents with names attached (i.e. consent forms) were stored separately from transcripts. Fourth, upon completion of the research the documents will be stored in a locked cabinet by Dr. Laurie Hellsten at the University of Saskatchewan for five years.

The main potential for harm in this research was the sensitive nature of topics to be covered during the interviews. I have attempted to reduce this potential for harm by ensuring that the women were informed of the subjects to be discussed at the outset of the research and that the women were informed of their right to withdraw before each interview. I informed the women of the possibility to stop the interview at any time, to not answer any questions or to take a "time out" from the interview if needed. I also provided a list of potential referrals for support at the completion of the second interview. This list included free counselling and support services available to the women, such as the abuse groups with Family Services Saskatoon and the Adult Mental Health intake line. Each woman was given a list of available services in her area at the completion of the second interview. The list of services for the Saskatoon area is attached as Appendix M. As well my supervisor, Dr. Laurie Hellsten, and my committee member, Registered Doctoral Psychologist, Dr. Stephanie Martin, were available for consultation in the event of any participant expressing distress during an interview.

The results of this study have been used for fulfillment of my thesis requirements for a Master's of Education in School and Counselling Psychology at the Department of Educational Psychology and Special Education, University of Saskatchewan. Results may also be used in a conference presentation, a publication with the FASD Support Network of Saskatchewan, or

submitted for publication in an academic journal. Participants were informed of these purposes within the consent form.

CHAPTER 4

RESULTS

The research question for this thesis was to explore the essence of the experience of birth mothers of children with FASD since the birth of their child. This chapter will discuss the results of the research using excerpts from the interviews with the women. I will do this in two separate sections. The first is focused on the context of the women's stories; where they have each come from and their individual differences. The second section will be a description of the main themes, which are used to illuminate and describe the meaning of being a birth mother of a child with FASD. The words of the women from the interviews are used throughout, with speech patterns such as "um" and "you know" removed for improved clarity. Pseudonyms are used throughout this document to protect the privacy of the women. All of the women were given the opportunity to choose a name that was meaningful to them to represent themselves within the research; two women chose their own pseudonyms and two were chosen by me.

The Importance of Context

As I worked through this research I began to contemplate the idea of context. In this research, I sought to understand the essence of the experience of being a birth mother of a child with FASD. Within the interviews, stories of childhood and adolescence lives intertwined with stories about being birth mothers of children with FASD; the women all discussed being a birth mother as connected to their early life experiences. It became clear to me that to honour the women's stories, I must begin by giving a brief description of each woman's early life. By examining each woman's story individually, we are able to accomplish two things: see what elements of this phenomenon are similar across these very different life contexts and also recognize the importance of early life experiences in the shaping of the experience of being a birth mother of a child with FASD. In order to provide context I will now present a description of each individual woman and her story.

Individual Journeys of the Birth Mothers

Each brief description of the women's lives will be preceded by a quote from her interview which captures one of the main teachings from her story.

Lynn: "Today I wouldn't change them for what they would have been. I'm happy with how they are today." Lynn is a mother of five children with FASD, and a grandmother of eight children. She has lived on a Saskatchewan First Nation reserve all of her life and came from a

large family headed by a single mother. Lynn's childhood was spent moving from school to school; on the reserve, in town and in residential school. Lynn describes alcohol as always being a part of her life; her mother and the whole family were always drinking. Lynn describes herself as the "little mother" as she was the oldest of the children left at home alone while her mother was drinking. Lynn experienced sexual abuse from a family member as a child, and has spent much of her life healing from that experience.

Lynn was always extremely independent and often had to learn life lessons on her own. For example, she discussed how she had to learn about pregnancy and child birth on her own, stating, "I never was told that you get your period, or never was told about having a baby or all these things. Or never was told about relationships or anything. Just kind of like all had to learn by myself." Lynn had her first child at age 17 and described never being told that she should not drink while she was pregnant. Within Lynn's community, alcohol was a constant presence, and it was common for women to drink throughout their pregnancies. Lynn describes herself as an alcoholic at the time that her children were young.

At the time of the interview Lynn had been a recovering alcoholic for seventeen years. She had managed to quit using alcohol and begin her healing shortly before she discovered that her youngest child had FASD and her other children likely did as well. Instead of letting this new sorrow break her, she made a decision to learn as much as she could about FASD to become an advocate for her children and for others living with FASD. Lynn now works as a support worker for young mothers. She is one of only two women in her community who have spoken out about their drinking during pregnancy in an attempt to educate others and gain supports for individuals living with FASD. Today Lynn is a leader in her community, and she amazed me throughout our interviews with her wisdom and insight about her life as a birth mother.

Ruth: "Being beaten up, being knocked out, being left behind." Ruth's story left me feeling overwhelmed with the amount of hardship and sorrow she had suffered throughout her life and the strength she had to keep going. Ruth describes her family as being heavily involved with the street life and with drugs and alcohol. Ruth lived in a variety of homes growing up; in foster care, in residential school, with her biological mother, with her biological father, and with extended family members. Ruth's mother was an alcoholic for all of Ruth's life, and Ruth's father has told her that her mother also drank while pregnant with Ruth. Ruth also describes being sexually assaulted at the age of 14 and being blamed by family members for the rape.

Ruth had five siblings, but rarely lived with them growing up as they were all placed in different homes. She describes much of her alcohol and drug abuse as attempts to re-connect with her family and to fight loneliness and depression. Ruth states, “Growing up I suffered with a lot of loneliness and depression eh. And... I understand for me that’s why I chose to go drinking. Just always being alone and not having anybody around.” Ruth began experimenting with drugs and alcohol after she was raped, and began using with her family regularly at age fifteen. Her alcohol and drug use continued throughout her life and worsened over time to the point where she was using intravenous drugs, selling drugs, prostituting and living on the street.

Ruth had her first child at the age of 15; she parented him from birth and remains close to him to this day. Ruth had five subsequent pregnancies and has parented some of her children for periods of time, but other than her eldest child they are currently all in the care of family or the government. Ruth used both alcohol and drugs during all of her pregnancies except her second child, at the time of that pregnancy she was living with a supportive foster mother and going to school.

Despite a lifetime of suffering, Ruth is currently on the path to recovery. She is employed, living in a stable home, sober and fighting to have contact with all of her children. Ruth taught me a great deal about the ways in which our system fails those most vulnerable and the damage that is caused in splitting up family members. Ruth’s strength is inspiring as she continues to “Just keep trying and move forward.”

Amanda: “And if I had not been able to forgive myself, you know I’d still be, I wouldn’t be anywhere. I wouldn’t be anywhere.” Amanda was the first woman I interviewed and I was nervous as we began our conversation. I quickly became comfortable with her warm smile and open sharing of her life stories. Amanda lives in Saskatchewan, with her husband and children. Amanda grew up outside of Saskatchewan in another Canadian province until her family moved to Saskatchewan when she was a teenager.

Amanda described how people look at her and judge her as having the “perfect family, the perfect marriage, she’s got it all.” However, that is far from how Amanda describes her view of herself and her life. Amanda was sexually abused throughout her childhood by family friends and much of her young life was shaped by her attempts to cope with that traumatic experience. Her teenage and young adult years were characterized by feelings of being unworthy of being loved and a search for love through relationships with men. Throughout her story she describes

her feelings and behaviours at that time in her life as “no sense of value for myself.”/ “I was pretty much there just to be used, that’s how I saw myself.” /“I was nothing. I was nothing and that’s exactly how I felt.”

Amanda coped with these feelings of inadequacy through her relationships with men and by using alcohol. Amanda eloquently describes this connection in her life as follows:

Because of the abuse I felt very worthless and useless and that no one would want me. And the drinking was a way that you could just, you could hide that, you didn’t have to think about that. You could just become somebody else. And there was a lot of men, men involved at that time too. And I guess what I wanted most in life was to be loved, and that’s what I was looking for, but at the same time the more I was involved with this, it just made you, made me feel even more worthless, but when you just kept drinking. I wasn’t drinking every night, but when I did drink it was a lot, it was a lot, yeah, so.

Amanda was 20 years old at that point, and she was binge drinking until she found out she was pregnant.

Amanda noticed her daughter’s constant struggles in school and with friends while growing up. Amanda parented her child with confusion, never knowing where her daughter’s constant difficulties came from. Her daughter’s behaviours became even more problematic in high school and young adulthood. It wasn’t until Amanda’s foster children were identified as possibly having FASD that Amanda considered her drinking during pregnancy as connected to her now adult daughter’s struggles. Amanda has since pursued assessment for her daughter and continues to support her in every way she can. Amanda has found self-forgiveness and works hard to be an advocate for her children with FASD, speaking out across the community about her experiences.

Irene: “Putting all the shame and the blame back where it belongs, because it wasn’t mine in the first place.” Irene grew up on a Saskatchewan First Nation reserve and is a survivor of residential school and of childhood sexual abuse. Irene was raised by her mother and was the youngest of six siblings. Irene also had early family experiences with alcohol; she remembers her mother starting to drink heavily when Irene was about eight years old. Irene’s family was plagued by sexual abuse throughout her childhood. She told a story of a healing circle she

participated in, “There was ... 22 of us in the circle. All admitted that we were sexually abused by somebody in that circle... And then we abused somebody in that circle.”

Irene began drinking at the age of thirteen, shortly after the sexual abuse stopped, and drank heavily until her thirties. Her four pregnancies occurred during this time period and she drank during portions of all of the pregnancies. Irene also describes how she was never told not to drink while pregnant, and how drinking during pregnancy was a normal part of her community at the time, in the 1970s. She stated, “People that knew should have told me but, all the people that I drank with you know, always said ‘Well make sure you eat so the baby eats.’ And I thought that was normal because there was lots of women in this community that I drank with that were pregnant.”

Irene’s life as a birth mother of a child with FASD was characterized by continued alcoholism throughout her children’s early lives. As a result she has been involved with child protection services and her children were apprehended for a period of time.

Irene learned that all of her children may have FASD after she had been sober for several years. She has since pursued assessment for three of her children, who were all diagnosed with disabilities under the FASD spectrum. Her eldest son has chosen not to pursue an assessment. Irene has learned a great deal about FASD since that point in her life and has spoken out in her community about being a birth mother about drinking during pregnancy. Living as a birth mother today, Irene is very much still a mother to her adult children and continues to provide support and guidance along the way. As I sat and listened to her story I noticed her sense of peace and tranquility and her positive outlook on the future.

Common Early Experiences

There are a variety of early life experiences that are common among the birth mothers. The stories are largely contextualized by trauma, abuse, violence and the women’s attempts to cope with these life situations. All four of the women are survivors of childhood sexual abuse. These experiences shaped the women’s journey towards becoming birth mothers, and also impacted their lives as birth mothers. Healing from this abuse and healing from the use of alcohol are connected for the women. Several women discussed how healing from the abuse was something that happened in addictions treatment. Irene describes this connection, “I think actually when I sobered up in ’9-, then I started feeling. Feeling something, like, dealing with all my stuff. Doing anger work on my own sexual abuse, doing inner child work, doing my own grief work. I started

to feel.” Amanda discussed the use of alcohol as a “way to hide”. For Irene and Amanda, the use of alcohol became a part of living with sexual abuse through the avoidance of emotions.

Three of the four women stated that alcohol was ever-present in their lives as children, used by family, friends and later their partners. Alcohol use was a normal way of life, it was not questioned. Lynn stated, “As we were young, growing up, our mother always had, there was always drinking in the family... we seen our mother, our aunties, and all drinking in the family when we were young growing up.” For Ruth, the use of alcohol and drugs became the only way that she felt that she could connect with her family and the common way that her family dealt with their own emotional experiences. She stated,

But yet, there, it's, you have to deal with the loneliness and the depression, you know and. For myself I've always struggled with that. The only way, only thing that I was taught was through drugs and alcohol. Drugs, alcohol and prostitution. You know that's what our family. They did that before anything else right. Yeah, so. And my family like, they all, we all struggle with addictions. We all do.

These early experiences with alcohol in their families seemed to lead to early experimentation with alcohol among the women themselves. Irene describes drinking heavily from the age of 13, Ruth from the age of 15.

The three First Nations women who were interviewed were all survivors of residential school. The link between residential schools and the experience of being a birth mother was clear in Ruth's story, who described her experiences of disconnection from family as being related to her subsequent abuse of alcohol and drugs. She stated,

My family did it so I didn't wanna be left out. Yeah, it was just, it for me it had to do with, my using was because I wanted to fit in with my family. Cause I was never with my family when I was younger. I went into residential school. Fighting depression, loneliness. Cause my Mom and them they were always gone, eh?

The women describe their experiences during their pregnancies as often stressful and chaotic. Ruth discussed living on the street during her last pregnancy, and described the difficulties of living with her mother (who was also suffering from addictions) when Ruth was 15 and pregnant with her first child. She stated,

And then the father, he didn't wanna be there... we weren't even together that long and then I ended up, yeah I ended up getting pregnant. My Mom told me I had to keep it. So I just dealt with it like that as best I could. .. And when my first son was, when my first son was born there was no food.

Amanda also describes her pregnancy as a stressful period in her life. She was scared, young, pregnant, single and living on her own in an unfamiliar city. She stated,

I was living with two girls at the time, I went on social services. And I think I pretty much just tried to get through the pregnancy. I did look for some type of work, I think I tried to do different babysitting jobs, but because of, obviously when you're expecting people know you're quitting. You can only do it for so long. So I lived in the city and I went out with this guy and felt terrible. Felt very terrible.

Ruth's knowledge that her alcohol and drug use may affect her children also contributed to stress during pregnancy. She describes feelings of remorse while using drugs during pregnancy:

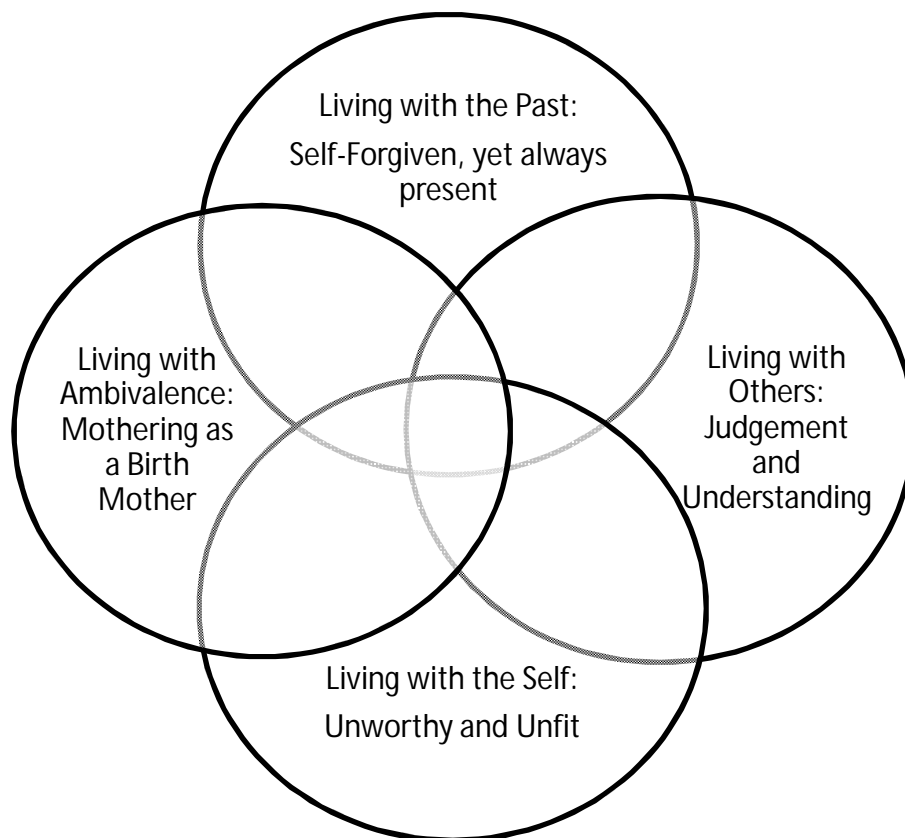
I have my baby, like if I keep doing this, I'm taking that risk of having an FAS child. And then knowing, knowing OK well, putting my, putting all my faith in God. Like please God, don't. Just help me through this. And begging, begging while I'm wronged everybody. Begging to God to just make my baby healthy.

The women interviewed in this study had lives filled with abuse, poverty and trauma. Their life stories and the commonalities found within provide a deeper glimpse into the experience of being a birth mother of a child with FASD. The women were all survivors of sexual abuse, and three women were survivors of residential schools. The women lived through poverty and described periods of great stress at the times of their pregnancies. For these women, the experience of being a birth mother of a child with FASD did not happen in isolation from other traumas. The lives of the women interviewed contained complex interconnections of abuse and poverty; being a birth mother cannot be truly separated from these early experiences. However, this research focuses on the lives of the women *as* birth mothers, since the time of their pregnancy. Thus, the following section describes the themes which illuminate the birth mothers' experiences with raising their children, healing, and learning about FASD.

Being a Birth Mother of a Child with FASD

In this section I will discuss the themes of being a birth mother of a child with FASD which came clear throughout the women's stories. As described in the data analysis section, each woman's story was carefully analysed using several different methods to extract essential themes which illuminate the experience meaning of being a birth mother of a child with FASD. In hermeneutic phenomenology, the word "theme" is used to represent the many pieces of meaning which come together to form a human experience. However, it is important to keep in mind that themes are also a reduction of meaning because they reduce a greater experience into a simple notion (van Manen, 1990). By attending to the stories of the four women interviewed, I have attempted to unearth the essence of what it is like to be a birth mother of a child with FASD. The experience of being a birth mother of a child with FASD centres around four themes: Living with the Past: Self-Forgiven, yet Always Present; Living with Others: Judgement and Understanding; Living with the Self: Unworthy and Unfit; and Living with Ambivalence: Mothering as a Birth Mother. These themes were interconnected and overlapping as is shown by Figure 4.1.

Figure 4-1. Being a Birth Mother of a Child with FASD: Four Themes



Living with the Past: Self-forgiven, yet Always Present

I came into this research with a profound curiosity about the experiences of guilt and shame felt by women who are birth mothers of children with FASD. Although I did not specifically ask about guilt or shame in the initial interviews, all four of the women brought up these emotions time and time again. Although I anticipated guilt and shame to be experiences of the women, I did not anticipate the many ways in which these emotions would be expressed throughout their lives. I will discuss the experiences of guilt and shame within several different subthemes in order to illuminate how the women are always living with the past, always living with the guilt and shame. These subthemes include: “It’s always present”; The way out of the darkness; and, And yet, still here.

“It’s always present.” The words guilt and shame were both used by the women, almost interchangeably, to describe their emotional experience of being birth mothers of a child with FASD. The women described these emotions immediately when discussing their lives as birth mothers, and described them as very difficult emotions to deal with, to heal from and to overcome. There were many times in the women’s stories when they described how painful it was to live with the past in this way, how their past actions were always on their minds. When asked about the presence of guilt and shame in her everyday life, Ruth stated,

It’s always present. Always. It’s just that I try not to show it. And that’s why I struggle today just to try and make changes. Three years ago, you know, I was addicted to coke and living on the streets, having my child on the street. And I live with that shame all the time. I chose to do drugs and I gave everything up for my addictions. It’s a daily shame and guilt. So it’s constantly, that’s why I try to do my best. I can’t be home, I can’t be by myself, because it gets me thinking. At one point I couldn’t even talk about my children. The moment that I would bring them up I would just get all overwhelmed and want to cry.

One aspect of this guilt and self-blame seemed to be a hatred of self, a form of anger. Anger was a commonly mentioned emotion by the women, usually directed at themselves, and sometimes at those around them. Lynn described feelings of anger at herself and at others,

I just hated myself, I couldn’t stand it. Well, how the heck? Why did I do that and now they’re like this. That very angry feeling at me. Because nobody didn’t tell

me, and but like I should'a known better. Like somebody should'a told me this. Like that, all different kind of things came at me at the time. It was hard. It was a hard time at that time because I wanted to blame people, but then the most of person I wanted to hurt and blame was myself. And because if I didn't drink then my children wouldn't be all affected, wouldn't have brain damage, wouldn't be having struggle in their life.

As can be seen in Lynn's statement, the experience of guilt and shame was often amplified and brought to the surface when thinking about the struggles that their children currently have as a result of their disability. Parenting children with FASD presents many challenges, even as children grow into adulthood they often continue to struggle with making decisions and becoming independent. Being present through these difficulties that their children faced was a constant reminder for the women, leading to continuing guilt and shame throughout their lives. Since these women are still mothers to their children; they live with this reminder on a daily basis. Ruth described this experience as follows:

I see the signs, I see things in him that I have done. Like having children from different women, you know, for myself from different men. And not having a home, just being alone, my son does struggle with that now. And it hurts. And so I do, I carry lots of guilt and shame.

For these women, guilt and shame was such an ever-present part of being a birth mother of a child with FASD that it was a primary emotion upon "finding out" that their child may have FASD. Three of the women had a moment of realization when they found out about FASD and how it may be the source of their child's difficulties in functioning. Each of these women discussed guilt and shame as immediate emotional reactions at this time of "finding out". For these women, the emotions of guilt and shame occurred during this first moment of realization that FASD *may* be the cause of their child's difficulties, often long before their children received an actual diagnosis. I use the terms "finding out" in quotation marks throughout this discussion since for these women, this moment of "finding out" about FASD was not necessarily at the time of diagnosis or assessment for their children, but rather at the first moment that they found out what FASD was, the first moment they realized that their drinking during pregnancy may have harmed their children.

For Amanda, that moment occurred when she was at a conference learning about FASD, since she recently learned that her foster children likely had FASD. As she heard about the experiences of a young woman with FASD, she began to connect the characteristics and disabilities to the many struggles of her own biological daughter. Amanda thought back to drinking during her early pregnancy with her daughter and realized that this was likely the key to her daughter's constant difficulties. She described her emotions at that moment as follows:

I could feel my heart pounding. And I don't even know if I was keeping it inside or if other people could see what was going on. But it was extremely hard to sit in my chair. It was the anxiety, the panic feeling of just wanting to get up and run. I just wanted to run. It was like, I was just saying, "Lord, not this too. Why does this? You know, why this? Hasn't there been enough already? Why this?" ... And the guilt, and the shame and wanting to go to her at that point and just take her and just tell her that I was so sorry.

For Irene, this experience of "finding out" came when her cousin told her about FASD and how her children might be affected since they had drank together during their pregnancies. She felt so much guilt immediately that she became angry and defensive with her cousin, not wanting to hear about it. For her, the guilt of possibly having caused her child harm impacted her ability to even think about assessment for her children in the beginning. Irene stated,

And then the FASD started coming out and ---- [my cousin] started coming around and I was just angry at her and didn't want her to talk about FASD and I just didn't want to go there because the guilt was so strong, the shame was really, really powerful. After she'd leave I'd get really, really mad at myself and I would cry. I did lots of crying, I never knew that I could cry so much.

For Ruth, this experience of "finding out" was slightly different. She described knowing during her pregnancies that her drinking might harm the fetus. She described instant remorse as she was using alcohol and drugs during her pregnancies, but despite these feelings of remorse, she found herself unable to stop. Ruth shared,

And then after I'd get high, I'd sit there and then I would try and figure out, you know like, "Why am I doing this? This could do something to my baby."... Like

everybody'd sit there be laughing and having fun and then I can just remember just in my mind I'm like, "Oh my God, what did I do? Why did I do this? I shouldn'ta did this."

The guilt and shame described by the women in reaction to the knowledge that drinking during pregnancy may have harmed their children was so powerful that they found it almost too hard to handle in the beginning. The emotional experience left the women feeling lost, overwhelmed and helpless; they wanted to give in and give up. Lynn discussed how her guilt and shame about drinking during pregnancy almost drove her back to her addictions as a way to cope with her emotions. She stated, "Right away, you wanna go back to drinking. I felt like going back to drinking. Because I hated myself so much because of what had happened at the results of drinking while pregnant."

The women discussed how drinking alcohol had become a way to deal with life's struggles, and that way of coping did not stop with the birth of their children. Dealing with the guilt and shame made recovering from alcoholism all the more difficult for some of the birth mothers. Ruth described how she would leave addictions treatment because the reality of her emotions and dealing with her previous actions were just too hard to face:

So they got me into there [treatment centre] and I only stayed for about two weeks and then I [left]. Because reality... you're not high no more so then I have to start thinking about reality. And the emotions start coming. And just the thought, you know that, I have to answer to all of this.

These always present emotions of guilt and shame took a variety of forms in the women's lives. For these women, living with the past was not only about living with the guilt and shame of drinking during pregnancy. The emotions of guilt and shame were mentioned repeatedly by the women in regards to many past events related to mothering and their own lives. The knowledge of their children's disability seemed to be another element in a long line of interconnected traumas and events which caused similar emotions for the women. Amanda had told herself "Lord, not this too," when she first realized her daughter might have FASD. Lynn also described a moment of feeling overwhelmed by having to deal with yet another obstacle in her life. She described how she found out about her children had FASD right after she had struggled for months to become sober. She stated, "After that, having to deal with all this new information that

you drank with your children and now look at your children are like this. And that was another big blow for me.”

The women each had different reasons for feeling guilt and shame for their pasts. Ruth discussed the constant guilt and shame that she experiences related to the continuing drug and alcohol abuse that led to her losing her children to government care. She stated,

Knowing that you, K, I chose addictions over my children, that’s the shame. Just knowing what I gave up. I gave up my happiness around my children. Seeing them get hurt, scrape their knees, or coming up to you and holding you and telling you that they love you, right? It just hurts. And I know I don’t get that no more. For what? Just for using. Yeah, so I hold a lot of shame.

Irene’s children were taken into foster care while she was in alcohol and drug treatment. While her children were in foster care they were sexually abused, and Irene described her emotions at the time as follows:

After I’d come out of treatment, and finding out my boys were sexually abused in that home. Which I thought was really safe cause it was [my family member]’s home. And then again I was so hard on myself, so much guilt and so much hurt. Of what happened to my children.

Ruth described how she feels guilt for a variety of actions she took as she was living life on the streets. She shared,

And be there with a partner you don’t even wanna be with, and sleeping with different men, just for a place to sleep. It’s awful. That’s where the guilt and shame is, ‘cause as women, we don’t wanna be doing that. It’s just the bad side of it all.

Several of the women talk about guilt returning to their lives in another way after “finding out” about FASD. The women express guilt for not knowing, not realizing that their children often didn’t understand, weren’t capable of what was being asked of them. Amanda stated,

I don’t even know if you can describe the guilt. The guilt of knowing that I did that, but the guilt of knowing how misunderstood she had been her whole life. And how I had seen her, and how everyone else had judged her and misunderstood

her and had I known it could have been so much different... I think when I see her now; knowing that and I look back upon her life everything just makes sense. It just, everything just clicked and I wish I could go back to each situation and each person that ever saw her, I knew was looking at her.

Irene detailed how she reflected on instances with her children, now understanding that they weren't disobeying, but rather not understanding her. To help herself get through these memories she has to remind herself that she didn't know at the time, she didn't understand either. She stated,

And then when my younger ones were born I would tell them like, "Ok... go downstairs, get your boots, get your jacket and come on, we're gonna go now." And my son is standing at the bottom of the stairs, four years old, looking at me. He's sitting, "What do I have to get?" I said, "You have to get your boots!" and I would just yell at him. And my younger one would be just standing there, "Well I thought you told me to get this." He'd be getting something else. I found it really shocking I guess, when I learned more about FAS and how I treated my kids. Again there was guilt there. Oh no, they didn't even understand and I treated them that way. And then I thought about myself, well, I didn't understand either, why am I so hard on myself? I just need to learn to have patience. And I need to be their external brain, and I need to help guide them.

As discussed earlier, the experience of being a birth mother of a child with FASD cannot be truly separated from the rest of a complicated life. From the outside looking in, it may seem that the understanding that your own drinking may have harmed your child would lead to such intense guilt that it would be all-encompassing. However, for these women, this form of guilt is a reaction to only one of many hurts, one added on from the many abuses they have survived and the many events they regret throughout their lifetimes. This pervasive guilt and shame becomes a constant presence in the women's lives.

The ever present emotional experience of guilt and shame entered into various aspects of the women's lives, including their relationships with themselves and others. An important aspect of this relational experience of guilt and shame is how these emotions entered into the relationships with the child or children with FASD. Irene and Lynn both talked about frank conversations that

they had with their children about their drinking during pregnancy. Lynn shared the story of explaining to her children what FASD was and apologizing to her children at a holiday dinner. She stated,

I was still recovering at that time, they're all seated around and I told them that, I more or less said, "In anything that ever happened in your lives, I'm so sorry if what I did to you children, how I hurt you, or what happened. In each and every one of you I had no idea that I wasn't supposed to drink when I was carrying each of you. So now today each and every one of you have a disability of FASD from me drinking when you were in my womb." So they all looked at me, and they put their heads down, and I didn't know, they didn't share what they thought at the time that I told them.

Ruth appeared very emotional as she told the story of her apologies to her newborn son:

Cause like he was taken right from the hospital, right. And I can remember just holding him. Saying my goodbyes to him. My apologies for using. You know, and I cried over him. Told him I was sorry. Had a few words. You know, and I looked into his eyes.

The impact of the experience of guilt on the women's relationships with their children is also evident in several women's discussions of the idea of "owing" their children. Three of the women discussed the fact that at the outset of their journey as a birth mother, when the guilt was the strongest, they felt that they "owed" their children and thus attempted to do everything for them out of this sense of owing. The women talk about this mostly as something that has happened in the past, before they began healing from their guilt, shame and anger. This feeling of "owing" can turn into a more positive form of support as healing occurs. Irene stated,

I was always there for them and I always will be there for them. But I learned to separate that because at first I was doing it because I felt I owed it to them. Because of the drinking that I did with them. And then again when I felt like that there would be more guilt and more guilt. Holy, I never realized that the guilt was really hurting me until I learned to let go. So now, I don't look at it as owing

them... I look at it as they need guidance. They need guidance, they need that exterior brain. So I'm really proud that I can help them like that and it makes me feel good, you know?

When I asked Amanda about her use of the word "owe" in her relationship with her daughter, she talked about how for her, this idea of owing her child is not a negative facet of her relationship with her daughter, but a way to try to support her and to advocate for her. She stated,

For all of her life she has been misunderstood, she has been judged, she's been criticized. And had a very hard life. And I don't feel I owe it to her in a way that, not in a bad way. It's just this is something that I can give back to her and try to help her and help other people understand her. And who she is. Even though I want them to see the good, not all her weaknesses. I want them to see who she is, but at the same time she does need help at times.

The women also described the impact of guilt on their relationship with their self and on their self-concept. Several of them discussed how they attempted to self-punish after "finding out". For example, Lynn stated that she was, "Just really, really self-punishing myself. I did kind of. Just really knocking hard on myself, really crying and just angry and just wanted to go back to drinking cause I just sobered up, eh."

Ruth talked about her life after her children were taken away and her downward spiral that led to increased alcohol abuse and thoughts of suicide. Elements of self-punishment were evident in her story about that time in her life. She talked about one of her lowest moments:

Telling myself this is what I wanted? I wanted drugs and alcohol over my children? Just wishing for death. Being beat up all the time. Just not even wanting energy to live anymore. You know, just give it up, it's not worth it. So I'd be pleading, how come you're not taking me? I just wanna die, just take me now. Just laying there and just putting my arm over and just allowing any kind of needle, don't even care, to be put in my arm.

The way out of the darkness. Irene described her understanding of the word shame as, "all black. It would be like I can't find my way out." She became lost in the shame, and had to fight

to get out. The women talked about the guilt and shame being ever-present, painful and powerful, but all four of the women also discussed the ways in which these feelings of guilt and shame have become less prominent over time. They talked about the ways in which they sunk down into the guilt and shame, but also the ways in which they climbed out. They told stories of being able to move beyond their own self-blame and become sources of support for their children and their communities. For these women, the experience of guilt and shame seems to be ever present, however it is not constant. The women experience ebbs and flows in the experience of guilt and shame and talked about how the intensity of the emotions have lessened over time.

As a student of counselling psychology, I am particularly interested in the processes that the women identified that have helped them to heal from the pain of being birth mothers of children with FASD. All four women talked about the importance of prayer and spirituality in their healing and self-forgiveness. Ruth talked about her journey with spirituality and healing:

After I went through treatment... they offered sweats and stuff, to attend. At your choice, right. I went in one. And then that's when I knew that that's what I needed in my life. I didn't need to pray, or, I just needed to be in that tent with everybody else. And just talk to God, with myself. Cry. Let it go. And just come out of there not feeling judged.

Irene shared a beautiful story about finding forgiveness through spiritual and cultural beliefs:

In the beginning when I was finding forgiveness in myself it was hard because it was just a word. It was just a word. Forgiveness was just a word. And then I compared it to guilt, and guilt was not just a word. Guilt was something really painful. And like shame. Shame was a dirty word for me, it wasn't a good word. But forgiveness was something different... I went to the Sun Dance, and to sweats, and that's what I really believe in. Prayer. And when I started to ask for forgiveness it didn't mean nothing. And I continued doing it and doing it and doing it, and actually really feeling it. Really feeling it. Relax my body. And do my meditation and I'd ask for forgiveness. Just awesome. Forgiveness means lots to me today ... it feels so wonderful to be able to forgive myself and not feel guilt

because of what I did in my life. And putting all the shame and the blame back where it belongs, because it wasn't mine in the first place.

Several of the women also talked about the importance of having others around to support them in their journey to healing. Lynn described healing through the informal support of her community and family members, saying that her healing happened through,

I think a lot of support. A lot of talking to my sister. Come and share with her and because we always talked together and we'd cry and cry and talk together. My other sisters I had too, I'd talk with them. And I'd find elders to talk with them and other friends that I had. And at that time, we would still go into the sweat lodge too.

Amanda talked about this need for support through the support that she has received through an organized group of parents of children with FASD. She stated,

Just meeting other mothers and other people through the support network has been incredible. It's the support that I have never, ever had throughout my life. Of women that have gone through or know, are dealing with the same things and I've never felt so in place in my life.

As I have discussed in several places, being a birth mother is intertwined with so many other experiences of trauma and abuse in the women's lives. It appears that healing from many other traumas was interconnected with healing from the guilt and shame of drinking during pregnancy. Lynn confirmed this with her discussion of the process she has taken in coming to acceptance and healing:

It took a long time for me to get over that and to finally accept, finally accept, Ok, what's done is done... At that time, after I finally accepted it and dealt with my anger and all my self-blame, I took it upon myself, I was sobering up and going to meetings and going to treatments and trying to find ways of helping my emotional self especially from when I was growing up dealing with all that abuses. The sexual abuse, emotional abuse, the verbal abuse that was put on me while growing up. Dealing with all that and then, now something else too, to help myself with.

And yet, still here. The stories of healing, of self-forgiveness, of climbing out of the shame permeate all of the women's stories, to the point where they have come beyond the shame in many ways. And yet, they all mention times when they recognize that guilt and shame is still present. For example, Lynn talked about her recent discovery that maybe sometimes she still acts out of guilt in relation to her children, even after all of the healing that she has done. She stated, "Now I find out, now... that I am still self-punishing myself. Yet. Still guilt, having some guilt and some grief of what had happened years ago." Irene also shared how guilt sometimes "creeps back in" to her life to this day:

Sometimes too I wonder, will the guilt ever go away? You know? Seeing my children and seeing the frustrations that they go through in their own lives. And then Friday my son was down from up north and it was good to, like I really enjoy all of them being home at the same time, but yet I could sense the frustrations that they have because it kind of sends a vibe in our home. When they don't understand one another. And then the guilt kinda crept in, seeing all four of them. Otherwise I kind of like accept what has happened and I say a little prayer to be able to help myself.

These four women have found ways to live with guilt and shame in their lives; they have found ways to use guilt and shame as fuel to become someone different, someone who is able to speak out for others and themselves. All four of the women are constant advocates for their children, for other individuals with FASD and for other women like themselves. They speak out about their experiences in this research and in other settings, creating further understanding. Lynn talked about being a birth mother of a child with FASD as her purpose in life and described how she started to come to that point:

That took a toll, but it finally pulled myself together, and hey, I'm gonna find out all about FASD. And then, and try to help. Help not only my own, but others. Cause I know I drank with other Moms, back in the old days. And that's what I thought to myself... I made it a goal. I'm gonna help these individuals, seems like nobody is really helping them. They kind of, how do you say, fall through the

cracks... So, that's kind of what I started thinking after I pulled myself out of the down spiral.

Amanda talked about moving beyond the guilt and the shame to a point where she can help her daughter and other individuals with FASD. She stated,

The guilt and the shame, that's, I mean that's there. I think I've... you come to a point of saying I can live back here or I can move on and I can do what I can to help. And that's where I am.

Amanda also spoke about how she has changed because of these events in her life, and the healing she has done. She shared about how she has changed from someone who felt that she was not worthy of anyone or anything, to someone who is able to stand up for herself and others:

And if I had not been able to forgive myself, I'd still be, I wouldn't be anywhere. I wouldn't be anywhere. I am able to defend myself now. I'm able to, I will go and if I hear somebody say something about my children I am there. And I will set them straight. You know, it doesn't matter anymore, I'm not saying that it doesn't hurt. But I am definitely, I'm not quiet. I'm so passionate about this right now that this is what I love to speak about, I love to share, I love to, given an opportunity. The forgiveness part has opened up a whole new world.

Reflections on living with the past. I entered into this research curious about the experiences of guilt and shame and how they impacted the lives of birth mothers of children with FASD. Guilt and shame were such an essential part of this experience that the women described these emotions as part of the primary experience upon “finding out” that their child had FASD. The impact of this guilt and shame in the women's lives was all-encompassing and debilitating at the outset of the women's journey with FASD. Guilt and shame impacted the women's ability to mother their children, to heal from past abuses and their own concepts of self. For these women, being a birth mother of a child with FASD means constantly living with guilt and shame, living with the knowledge of your child's disability and the link to your own past.

What I did not expect was the astounding ability of the women to heal from these emotions, to forgive themselves and also those who have abused them in the past and to move forward to

become advocates for their children and others with FASD. The women all acknowledged the impact of guilt and shame in their lives and their relationships with their children. But to a large degree the women discussed guilt and shame as something they had experienced in the past, something that they had worked through and overcome. There is an inherent inconsistency though, as the women discussed the guilt and shame as being in the past and yet recognized that on some level, it's always present. Despite the healing that has occurred for some of the women, they recognize that their past is something they will always live with as birth mothers. For these women, guilt and shame is always present, but no longer all-encompassing.

Living with Others: Judgement and Understanding

Another element which I was curious about upon the outset of this research was the community reactions to the women and their children. The women's stories contain discussions of being a birth mother in relation to others, in relation to experiences of both judgement and understanding. They also talked about their own expectations of judgement from others, their experiences of fear of what others will think about them as birth mothers of children with FASD. In this section I will discuss the women's experiences in their communities, their experiences of being birth mothers in relation to those around them. In order to better illuminate this experience I will use the following three sub-themes: "How could you do that to your children"; "I deserve it:" Expecting judgement; and The relief of sharing: Reactions of understanding.

"How could you do that to your children?" These women talked about significant moments that stand out in which others judged them for drinking during their pregnancies. Irene had the experience of being directly confronted by a man at a conference after she spoke about her experiences as a birth mother of a child with FASD. She shared,

I went to a workshop one time and this man asked me, he said, "How could you do that to your children?" And I was telling my daughter, it, I wait for that one day for somebody to tell me that...And when that man in --- [city], when I turned around, I smiled and, "How could you do that to your own children?" And I said "Thank-you for reminding me. Thank-you for reminding me," I said "Maybe there's something that I still need to take care of, but thanks," I said. And he looked at me and he walked away. I always waited for that day when somebody. I always wondered what my reaction would be, would I be angry, or would I understand?

Ruth told stories of feeling judged by the hospital staff as they checked her son for drug withdrawal. She shared,

So the doctors and stuff, right away they're judging me. Like, "I don't know why you people always have to take your issues out on your children." You know, saying things like that to me at the hospital.

The stories of judgement which seemed most hurtful to the women are those in which the child that has FASD lashes out at their mother for the cause of their disability. The mothers talk about their children being largely understanding in their reactions; however, moments of anger and blame did come up. Irene talked about her son's reactions as follows:

For my 19 year old there was blame. He said once, he once said, in the beginning, "So you drank with us. So you're the one that F'd us up." And at that time, I was going through the healing of dealing with the FAS, so that really hurt. Really, really hurt. And I let him say what he wanted to say. "So now because of you," he said, "We have to live like this."

"I deserve it": Expecting judgement. An expectation and a fear of judgement seemed to be a central part of the experience of being a birth mother of a child with FASD for some of the women. Amanda talked about this fear of others' judgement after the first time she spoke out to others about being a birth mother of a child with FASD. She stated,

When I was done, I think it took me a few days, you just beat yourself up. You beat yourself up and you wish you had just been quiet. You wonder what everybody's thinking, what are they doing?

Amanda also talked about this fear of judgement in telling her children about her drinking during her pregnancy with her eldest daughter:

I think, it was hard sharing about --- [my daughter] with them. Again I didn't want them to see their Mom, you know, this is what your Mom did to her. This is the type of girl, this is my past. This is what I did.

The experience of the expectation and fear of blame is intricately connected to the experience of guilt and shame for these women. They carry constant guilt and they blame themselves for the harm to their children, so they expect that reaction from others around them. That connection is clear in Lynn's story about telling her children about FASD for the first time:

My emotions is, I was crying. I was crying and yet I still carried guilt and still carried self-blame. Because, it was like, the feeling of "Ah! look what I did, look what I did!" You know, if it wasn't for me, you wouldn't be brain damaged. You wouldn't go through. Because I know and understand now that this disability is a life-long and it won't get better like a sickness. Yeah, a lot of emotional, I was crying and in tears and I at that time, I even offered, I even said, "Well, say what you need to say, even if it's harsh, or do what you want to do. Even if you're, even if you need to strike out, go. Go. Do it. Because I deserve it." Like, that part, like I was, I felt that way.

At that time in her life, Lynn was living with debilitating guilt and self-blame. Because of her internal experience, she expected that others blamed and held her accountable. She expected that her children would blame her and punish her the way she was punishing herself.

Ruth shared her perspective on how she feared being judged while pregnant and using drugs and alcohol. This fear made it difficult for her to ask for support and influenced her decision to hide her drinking during pregnancy. She stated,

I hid it from the doctors. Every time I knew I had an appointment I wouldn't get high. I would stay clean for a while and whatnot eh. Then I wouldn't drink... And then when every time the check-ups would come they'd ask me what, "Am I using, am I smoking?" and I'm like, "No, no, no." But I'd lied about it eh... Well I felt guilty 'cause I knew I was lying, I knew. But I didn't wanna have my kids taken from me.

The relief of sharing: Reactions of understanding. An inspiring part of the women's stories were the people who reacted not with judgement, as the women feared, but with compassion and understanding. Amanda talked about the first person she told about being a birth mother of a child with FASD:

When I shared with her, I just knew she knew, she understood, there was no judgement. There was no criticism. There was just a heart that knew and just understood. I think it was a relief to be able to tell someone, it was a relief to be able to share it. I think she was the, probably one of the best people to be the first to tell. At least to not have the judgement come anyway. But there was complete understanding on her part.

Lynn talked about the positive support she received from members of a class that she took shortly after finding out that her children had FASD, and how that support helped her to heal:

I'd cry with my teachers, with my instructors, and told them that I'm a birth Mom, and introduced myself at the beginning of the class, 'cause there was only like 3-4 of us at that training. And they understood... I got lot of positive support to help me along, and "Lynn, you didn't know better then," like, "Ok, now you're here, you can help them now." You know, like that.

Reflections on living with others. These women experienced situations in which they were judged and blamed for drinking during their pregnancies, both by strangers and by their children. However, what seemed most prominent throughout their stories was the expectation to be blamed and stigmatized, an avoidance of talking to others out of fear that others will react with judgement. As the women healed from their own guilt and shame, they seemed more able to speak out, to talk about being a birth mother with less fear of others' judgement.

For these women, being a birth mother of a child with FASD means a constant state of interaction between self-blame and the expectation that others will blame in the same way. Experiences of blame and negative reactions from others seem to be what is expected from the women, and when they occur it is hurtful, but almost what they feel they "deserve." Reactions of empathy, on the other hand, were met with relief from the women. Just in the way that positive supports were cited as a way that the women healed from the guilt and shame of being a birth mother, these reactions of understanding assisted the women on their path to self-forgiveness.

Living with the Self: Unworthy and Unfit

As I reflected on the many stories of seeking and not receiving the support that was needed; the stories of isolation and loneliness; the stories of fighting for supports for their children, I struggled with what these experiences meant in the lives of these women. What does it mean to

be marginalized, to be pushed aside in this manner? What phrase would best describe this aspect of being a birth mother of a child with FASD? As I pondered this feature in the women's stories, I looked to the words of the women themselves. How did they describe their emotions in dealing with this marginalization? I came across two words in the women's stories that I felt best captured this experience in my eyes: unworthy and unfit. The women told stories of feeling unworthy of love, unworthy of support and addictions treatment and unfit to be mothers.

On the opposite side of the continuum, the women also told stories of empowerment and feelings of worth. Of seeking and finding supportive environments for themselves and their children, of overcoming their own addictions, of finding positive means of coping. The women's stories represented both sides of this spectrum of worth; however experiences of being worthy seemed to come later in these women's stories, after many stories of healing. This aspect of the women's stories will again be discussed in several sub-themes: Unworthy and unfit; "Why didn't they tell me?"; and "Today, I don't have to walk behind anybody": Being worthy.

Unworthy and unfit. The women's stories are filled with times that they felt unworthy of love, unworthy of support or unfit to be mothers. One time when these emotions are present is within stories of times when the women needed support and discovered that it was not there. Ruth, in particular, offered insight on the feelings she had about not having the support that she needed. She felt that supports were offered to her to help her children, but once her children were gone, she no longer deserved any help and was left alone to "wander". She shared,

How I felt, how I hated the government, taking my children away on me and not even giving me any support just because my files were closed. What happens after that? We're just, as people we're just left out there too. They don't have to help us now that they have our children. We're just left out there just wandering. And our kids are wandering in and out of different stranger's homes.

Ruth also talked about how she felt that she was simply a "nuisance" in the eyes of those who could have supported her. She stated,

My only friends I had were all street people. And the people that were assigned to me by social workers and stuff to help me. Well after they found out I couldn't, I didn't have a home anymore, I didn't have anything anymore, they just all left me.

Like I didn't have no support ... Nobody to even say, listen I need help. Use the system up so much and then you become a nuisance.

The early experiences of abuse and neglect in the women's lives continue to impact their daily lives as birth mothers of children with FASD. The women talk about constant efforts to cope with past abuses that continue throughout their lives. A part of the impact of that past abuse for some of the women seemed to be feelings of worthlessness, of being unworthy of love. Amanda talks about how she always felt unworthy, saying, "And to me I was a person that nobody wanted and nobody could ever love." and "Because of the abuse I felt very worthless and useless and that no one would want me." She also talks about how this experience of feeling unworthy didn't end with the birth of her daughter, being a birth mother meant continued experiences of feeling unworthy and unloved. She shared,

After I had her it was a real, it was really good but at the same time I wasn't over, it didn't change who I was or what I had been doing, so in a short while I was still back, every weekend I was at the bar drinking. I loved her more than anything. I loved her more than anything but inside I still was not anything myself.

The women also received messages of being unworthy from outside themselves, from those around them. Ruth talks about experiences with her mother in which messages were given to her that she was unworthy. She stated,

My Mom, just the things that she would say made me feel dirty. When I gave my son up for adoption, my second son? I can recall, one night when I went and told her that I was making a decision to give him up for adoption ... and she got mad at me. And, she called me, she told me only dogs give away their litter. And I told her well you must be a dog then, because you gave us up too. You know, that's just what I said to make myself feel better.

The feelings of being unworthy of love continue for Ruth to some extent to this day. For her, they seem to be again connected to guilt that she carries from her past. She shared,

I have a hard time getting hugs from other people's kids 'cause they're not mine. You know and I don't feel worthy. I don't deserve that hug. My own kids can't hug me, so why should I be getting hugs from other people's kids.

For Lynn, feelings of being unworthy were exacerbated with the knowledge of the harm that her children received from her drinking during pregnancy. She talked about what she would like to say to others that place blame on birth mothers of children with FASD:

You don't know how it is to be a birth mother. We carry lots, we carry lots. The guilt and the hurt and we put upon, like our own children, and then the hurt that we carry. Like, to carry your own hurt 'cause some of us we, well for myself, I felt so worthless after I knew what I did.

The women also received messages throughout their lives that they were unfit to be mothers, both from others and from themselves. Three of the women had their children apprehended by child protection services at some point during their lives. The women spoke of knowing that they were unable to mother their children at certain times due to constant struggles with alcohol use. Ruth tells the story of feeling that she was unfit to be a mother, unfit for anything, but at the same time she expresses her anger that she was not given the support that she needed to be a mother. She shared,

I would try and tell the worker I need help. And all's they would do for me is take me to the food bank just to go and get bread. And then they'd drop me off and figure that their job was done. And then after that, and then my kids did go into care. I did try to keep up with my bills, but it just became so overwhelming... I said, "I asked for you guys to come in and help me," I said, "Not to take my kids away." I said, "Where, where's the support for me?"... And then, that's when they took my kids from me. No access. Permanent guardianship order. And then so I got mad. And that's when I started saying well, the government said I'm not fit to be a mother, so I'm not fit for anything I guess. Might as well just stay where I am. You know, what's the use in trying.

The messages of being unfit to mother came not only from child protection services, but from the women themselves. Lynn recognized her difficulties in parenting while she was using alcohol heavily, stating that she could not parent during that time. However, there was sadness and tension in her story as she recognized that she was unable to parent, but she also recognized that she drank more after her kids were taken away. She shared,

Because I, of course, in my life, I could not take care of children. I was drunk all the time and leaving them at babysitters all the time and, and not take care of them. So this is why they took... [my children]. And then I was left home with my own, my partner and we drank and we drank and we drank and we drank.

Amanda's story contains many instances in her daughter's early life where she received the message from others that she was an unfit mother. She seemed to also feel herself as an unfit mother; that she wasn't doing things right and that she was an unfit wife, an unfit woman. Her young daughter with FASD had trouble making friends and was very "hyper". Amanda and those around her attributed these behaviours to something that Amanda must be doing wrong. Amanda talks about one of these instances:

At the time, I was young and I'm thinking, "Am I that bad of a mother that I can't?" Because our younger one would just follow suit there. She'd get just hyper too and then I thought, "Am I that bad that I can't control my own children or what should I be doing?" My Mom always questioned me, "You should be disciplining."

"Why didn't they tell me?" The women expressed anger at the fact that no one talked to them about the risks of drinking during pregnancy. Several of the women were so over-looked, so pushed aside that they felt not worthy of the knowledge about the harms of drinking during pregnancy. For example, Irene stated,

On the days that I would think about it a lot, my children, when I'd see them, and not understanding FAS and stuff like that, I would look at them and I wonder like all these questions of how come nobody told us? Why didn't they know? Why did they have to wait so long?

The women seemed to express sorrow and anger that they didn't know the risks of drinking during pregnancy, that no one told them. Irene stated,

If I, if I'd known in 197- that it was wrong, then I would, I probably would have changed, I probably would have been more aware. So I was kind of hard on myself like that for a long time. Like, my Mom should have known, you know those kinds of things. People that knew should have told me.

“Today, I don't have to walk behind anybody”: Being Worthy. The women also expressed moments of feeling worthy, feeling valued, feeling that there is a greater purpose for being birth mothers of children with FASD. One aspect of this experience occurred when women found supportive people or environments that provided the guidance and support they needed with their addictions or with their children. Ruth described the support worker that currently works with her, discussing the difference in attitude compared to the support workers that she has had in the past:

And I told her I'm still using, I said, I'm struggling but I wanna make change. And she didn't give up on me. She didn't give up on me. As much as I tried, I fell. I did fall and I, but every time that I was using I told her. You know and said “Well once you're done using,” she goes, “just come back.” She goes, “We'll talk when you're back. And then we'll see what we can do for you to make change.”

Ruth seemed to connect this experience of having this support, of being worthy in the eyes of someone else, with her ability to maintain sobriety at present. With a proud smile, Lynn described how she is worthy and needed in the eyes of her children and grandchildren:

‘Cause they look at their mother as a mom, a supermom, I guess they would look at me as a strong supermom that she can do anything that she wants to... That's how they look at me as “Mom knows, Mom'll figure it out.” So I think that's how they look at me today. Or if they have trouble with their little one, “Go call Grandma, call Grandma.”

Perhaps the most meaningful aspect of being worthy is finding that feeling within the self, of finding a meaning and value within oneself. Lynn has found this feeling of being valued in her

role as a mother and grandmother and as an advocate for people with FASD. She described how she has come to feel that she became a birth mother because it was her “purpose” to help people with FASD. She shared,

For me, over all, the whole thing that I’ve been talking with you all these times, over all, how I can come down to it, for myself is, it has to be happen this way for me in my life. It’s kind of like a purpose for me for my life to help individuals in this kind of disability, to help them, because there doesn’t seem to be too much people out there or doesn’t seem to be too much people to understand them... To me it had to happen this way for me to learn and heal from it and to help people. It had to be because this is like my life. ...It’s not a really, really, how do you say, this magnificent or this movie star plan. For me it’s like a humbling, loving, caring, purposeful life. That’s kind of how I see it.

Irene gave a description of her transformation from feeling like she wasn’t worthy as a person to feeling equal to and valued by others:

The best part of it is the healing part of it. Acceptance. Facing the problems head on. I used to, when I used to drink I used to walk with my head down, I remember, I was remembering that one time. I always walked behind my older sister all the time, when I was drunk. Or when I was sober... now today I don’t have to walk like that, I don’t have to walk behind anybody... It’s better for me to walk beside people because I know I’m not better than anybody and I’m not less than anybody.

Reflections on living with the self. For these women, feelings of worth transformed throughout their lives. Early life experiences, combined with the knowledge of FASD, had left these women often feeling worthless, feeling like a person without value. However, as these women moved forward in their journeys of being birth mothers of children with FASD, as they began to move beyond the guilt and shame and abuse, they began to find worth within themselves. As birth mothers of children with FASD, these women have had to fight to see themselves as worthy of love, of support, of being a mother. They have also had to fight to have others see them as fit to be mothers, to see them as valuable members of their communities. A

part of the healing in the women's stories is the transformation to seeing themselves as worthy, as sources of power and change in their own lives.

Living with Ambivalence: Mothering as a Birth Mother

This aspect of the women's experience should have been so obvious. It's right there in the name we have to categorize these four women: Birth *Mother*. The experience cannot be what it is without stories of mothering, without connecting these emotional experiences of guilt, shame, judgement and worth to the experience of being a mother. However, being a mother, the experience of mothering, is not what immediately seems to come to mind when people think of birth mothers of children with FASD. The thought of blame is immediate, thoughts of alcoholism often not far behind. Although the women's stories do contain blame and alcoholism, those experiences and all of the experiences that have been discussed thus far are intertwined with experiences of mothering.

Ambivalence is defined as "simultaneous and contradictory attitudes or feelings ... [or] continual fluctuation (as between one thing and its opposite)" (Merriam-Webster, 2010). Being a birth mother of a child with FASD, for this group of women who were all involved in parenting, involves stories of mothering: experiences of frustrations, of seeking the best for their children, of being guides in the world for their children who often have difficulty navigating their way through life. It also involves stories of confusion and conflict; of trying to mother through difficult times and complicated emotions. In this way, the experience of mothering as a birth mother of a child with FASD is filled with ambivalence: of knowing and experiencing conflicting emotions at the same time; of knowing that something is wrong, but not knowing what, of mothering through times when others thought they could not be a mother. I will discuss these stories of mothering and conflicting emotions within the following sub-themes: Always there; "Mom's not doing very good;" A balancing act: Protecting and letting go; and If everyone could see what I see: Proud mothers.

Always there. As mothers, these women were the ones who supported their children through all of the many difficulties of having FASD throughout childhood, adolescence and into adulthood. They told stories of being with their children through heartbreak, frustration and pain, through trouble with the law and through difficulties at school. Lynn talked about how it was for her when her son was going through some difficult times:

I'd be always crying and just going through a, one of these worry things. Worry, being so worried and just afraid that maybe one day somebody was gonna, police were gonna come knocking on my door and tell me my son's been killed. Or in a car accident. Or beaten or something. It was such a hard thing for me.

With humour, Irene talks about how she's the one that is there for her children as they confront every-day issues, the simple, daily problems that her children face with memory and understanding. She stated,

I have to photocopy his status card, and health card and he keeps that in his wallet. 'Cause he has lost them too many times. He said, "I need to go shopping," he said, "I'm running out of pants. I don't know where all my pants have gone." "Did you check your drawers?" I told him. [laughing] "This is where all my pants are!"

Amanda told many stories of how she is always there for her daughter; both in the past and to the present day. She described what it is like to continue to support and guide her adult daughter who now has children of her own.

Very exhausting for me when I know I need to be doing something for her or I'm running over to help her with her dishes or her laundry or just calm her down. And then having my boys, and keep them, and then my teenagers and keep my husband happy. Some days are very hard. Very exhausting.

Amanda also gave insight into her role as a mother, compared to her husband's role as a father to her daughter with FASD. She talked about how her daughter's behaviours have caused problems in their relationship, but as a mother, she is the one who always must be there for her child, no matter what. She stated,

There was a lot of conflict. There was definitely a lot of conflict. A lot of things were, I think my husband felt that she was coming always between us. And a lot of her behaviours and the way, just how she was ... a lot of my time was taken up with her, which is normal for a mother as well. But there was just a lot of, a lot of things he didn't understand. And a lot of things I didn't understand either but as a mother you just, you take care of your child.

As part of being always there for their children, the birth mothers were there through many times of confusion over their child's behaviours. There were stories of knowing that something was wrong, but not understanding what it was or how to help their children. For Amanda, who didn't "find out" about FASD until her daughter was an adult, being a birth mother to her young daughter was filled with moments where she knew something was just not right. Amanda was also in a situation where she had several other children of her own and in her own extended family that she (and other members of her family) could compare her daughter to. This left her confused about why her daughter just didn't "fit in". Describing an afternoon when her daughter had friends over to the house, Amanda said,

Another thing that was hard for me to understand was why she couldn't keep friends or why there were problems with her friends. She'd have some girls, or girls would come over from school and she'd end up being just this uncontrollable child and I'd have to bring her friends home because they were crying or scared or didn't know. And --- [my daughter] was just out of control... She was doing things that I couldn't figure out why on earth she was doing them.

Lynn had a similar experience of confusion with her son, who was continually being sent home from school for aggressive behaviours,

I just like frustrated. I don't know what to do. What else do I do? And the only thing that I could do at that time was just take him home. Take him home with me. Then he seemed calmer at home, sort of played around at home, outside and that. But at school he was a different, he was just aggressive and getting mad at the teacher. He couldn't understand, maybe at that time, the teachers didn't know how to teach him because of his brain damage. And so he was getting frustrated, 'cause, "I can't! I can't! I don't know how, I don't know what to do!" And then that's when he'd lash out, and throw little tables and hit the teacher or bite, start biting, and pull hair. He was only seven, nine years old and he was already doing that already. So I don't know how many times I'd come to the school and, and you're to the point of being in tears. And I'd take him home, what do I, what else do I do?

As part of this always being there for their children, the women also told stories of always seeking supports, always seeking answers for their children. Whether they were at a point where they knew their child's struggles were caused by FASD or not, the women were constantly seeking something better for their child. Lynn talked about searching for addictions treatment for her son and his wife:

So I'm trying to set up treatment for both of them. A seven week treatment for them. With their baby, a whole family treatment ... But I had frustrations when he was eighteen, nineteen, we were trying to get help for him because of his drugs and drinking. I phoned all over, all the treatment centres. They couldn't take him because he had FASD, a disability. They said they had no workers educated in that area to help him in the treatment centre. It was so frustrating.

Amanda's experiences of seeking answers for her daughter involved searching for an explanation for her daughter's behaviours throughout her childhood and teenage years. She described some of these times as follows:

I think we looked at different, because someone had mentioned the ingredients in the lunch meat. Or maybe there was different things I was giving her that she shouldn't have. So I knew there was something. But it wasn't 'till later on when she was, just before she became pregnant, or after that. When I had called my doctor a few times and said, "Please, could it be bipolar, could you somehow, when she comes in to see you, could you somehow question her or find out or something without her knowing that I called." I did that twice.

"Mom's not doing very good." In contrast to being the one who was always there, the women all had periods of their lives where they struggled to mother their children. For these mothers, alcohol continued to be a part of their lives as they mothered their children. These four women all drank during pregnancy; that is part of the meaning of being a birth mother of a child with FASD. However, pregnancy is merely a small moment in a life; the use of alcohol began much earlier and continued much later for these women. This aspect of being a birth mother was prominent in Ruth's story. Her eldest son was with her through most of the ups and downs of her

life as she struggled with her addictions and poverty and she cared for three of her other children for periods of time as well. She describes how,

I ended up just going too far with the nightlife and stuff eh and wanting to hang out with everybody on the street rather than be with at home with my kids. My kids were getting older, my son was getting older and he could watch them.

‘Cause I’ve found that’s what I was starting to do too was what, what was done to me by my family leaving them with their siblings.

Amanda’s children were not taken into foster care, but she also recognizes a time in her life when she was a mother who was struggling to be healthy, not doing very well. She stated,

If I did not have my family at that time I probably would have had her taken away ... there were times that I would have, my cousin would come over to our house, to where I was living in the city and watch her. And I would just come home, you know whenever, five o’clock in the morning. And I don’t know what I would have done in the situation I was in if I did not have my family, I don’t know. I don’t know what I would have done or where, what I would have done with her. Would I have done the same thing? I don’t know. But it was still, the past had such a hold on me that it wasn’t just something I could, or I wasn’t in the position to just give it up then. Even though I would have done anything for her, I can say that, but it’s still, you know.

Ruth talked about how she always tried to explain to her children what was going on, to make sure that they knew that she loved them. She shared,

With my children, every time that I’ve had them in my care, I’ve tried to talk to them ... Give them hugs. Tell them that they’re loved. Cause like when they went into care I told them what was happening. And I explained to my children, “Mom’s not doing very good. She’s not healthy anymore. My, you see Mom’s drinking. You know that we’re not supposed to be doing that.” I’ve always tried to speak with my children.

One aspect that comes through all of these stories of addiction and struggling to mother is that the women loved their children through it all. They wanted to be mothers, to care for their children. Lynn talks about how the struggle to get her children back from foster care was part of what helped her to stop drinking, to become healthy. She stated,

They asked if I want to do something with my life, like sober up and try to take care of your kids. ... And I cared for my children, as much as I drank I still loved and cared for my children... to me that is why I took that step at that time to go to detox.

Another part of this element of struggling to be mothers to their children involved the women's experiences of feeling that they were "bad mothers." Since these women pursued FASD assessments for their children when most of their children were grown, there were many times during their children's childhood that their children were perceived as "bad" since others could not understand the child's behaviours. As mentioned, the women were confused and frustrated with their children's behaviours, something wasn't right, something didn't make sense. The women were seeking answers, seeking supports, but those around them often saw the women themselves as the problem, the reason that the children were "bad". This aspect was strongest in the story of Amanda, who had many experiences of others telling her she "spoiled" her daughter, she "needed to discipline", she needed to "toughen her up", that maybe she was feeding her the wrong type of food. These experiences started almost immediately for Amanda, when her daughter was just an infant. Amanda shared,

She cried, she cried. I think she was only a few days old and I was with some friends with her and I laid her, just put her down in the bedroom and she would scream and scream and scream and everyone was telling me how much I had spoiled her already. I had just spoiled her? I couldn't, I think, how could I spoil her so soon?

The idea that her daughter was spoiled, that these behaviours that her daughter was showing must be Amanda's fault continued throughout her childhood as Amanda was given various messages from teachers and family members that she needed to do something to control her daughter, that these behaviours must be her fault. She shared,

Knowing what we know now... I guess if I had known then, we always treated her as it was just bad. Bad behaviours or just like she was strong willed or stubborn or whatever it was, but it was just always we saw it as you know she was just being, being bad. Or she was spoiled. They would say, like everyone said I was - or not everyone - but many times I was told she was spoiled.

Amanda herself was confused and questioning her abilities as a mother, especially at this time in her life when she felt so unworthy, so unfit to be a mother. She stated,

I never stood up for myself. I never stood up and said anything back about what they, it was just, I would just defend --- [my daughter], protect --- [my daughter] and do whatever I could do. And then you're accused of being over-protective by everybody.

A balancing act: Protecting and letting go. Since the birth mothers are the ones who are “always there” they expressed tension in knowing how much support their children need, especially as their children grow into adulthood. How much can I let go? This is a dilemma faced by all mothers to some extent, but for birth mothers of children with FASD it becomes amplified. The women talk about how they have felt that they were too “over-protective” since their children’s early childhoods, and yet they recognize that their children need more support, more guidance and will continue to need that support throughout their lives. Amanda talks about how she would try to protect her daughter in her childhood:

It was heartbreaking. She always seemed to be the one at gatherings, when my husband’s nieces and nephews were there, or whoever, she would be the one that just seemed to not quite fit in. And I always felt like I was watching over her shoulder, to, to protect her, to make sure that she was being treated fair, that she wasn’t being picked on.

Lynn described the point that she is at now in her life as a birth mother; how she is trying to let go, to not be so over-protective and yet to still provide guidance. She shared,

I got too over-protective for them. Even though they’re getting older I got very over-protective. Yet today, now I’m learning in myself that they’re at, yes they do

have brain damage, yes they have struggles at times, but now what I can do now is be supportive and be there for them. And always let them know that I love them. I love you; I'll be there for you. And give them guidance where and when they need it.

If everyone could see what I see: Proud mothers. Through all of the struggles with their children's behaviours, the women all managed to talk about the amazing gifts that their children have. This experience of pride in their children could be similar to the experience that any mother would have; mothers often talk about their children's gifts, their children's accomplishments. However, part of this experience for birth mothers of children with FASD is the feeling that others do not quite see what they see in their children. The women talked about their children's gifts, and how they wished others could see them, if only others could concentrate on their children's strengths instead of labelling them. As mothers, they have constantly been "protecting" their children, constantly watching them, seeing others misjudge and misunderstand. So as mothers they also try to help others understand, help others see their children's gifts. Contradicting emotions are present again for the women, as they recognize their children need support, but wish others could see the good in their children as well. Irene talked about how her son and other children were labelled as "dumb", and how she sees it differently:

My son was in the structured learning class they called that at that time. And really labelled that class because there was people called them the dumb class, stupid class. And there was five boys in there and they were awesome boys, they just needed somebody to listen to them.

Irene also talked about how her daughter has so many strengths that the doctor who assessed her didn't see. She stated,

It was really interesting to hear what the doctor had to say, that she was weak in a lot of areas, but it doesn't seem like it, in she's, teaching in school, she's helping the kids ... and she does all kinds of nice stuff eh.

Amanda talked about how her daughter is able to do so many things despite her struggles with FASD, saying, "When you see everything else, and then yet she is able to do things that most people would never even contemplate doing, it's incredible... I am very proud. Very proud

of her.” Lynn gave many examples of the gifts that her children have and the need to see the positive in individuals with FASD. When talking about the advice that she would give to a young woman who is beginning the journey of being a birth mother of a child with FASD, Lynn discussed how people with FASD are seen in society, and how she sees something different:

For me, I see all the FAS individuals as gifted individuals. I don’t look at them as how people put them down as trouble-makers, they’re not good and stuff like that. Not to me, I don’t see that. I try to find that little light in each one of them. Because each one of them carries a gift. I know, because a lot of them are singers, a lot of them are dancers, a lot of them are artists, a lot of them are comedy. Even my own youngest is hands-on with wood-working and, very, very, very gentle and kind and loving... I’d just, I’d tell this young, this lady, accept them. That’s your child. Accept them, love them.

Reflections on living with ambivalence. The women’s stories of mothering their children are filled with an ambivalence that the mothers have negotiated for all of their lives. They love their children and want to mother their children, yet they all had times when they struggled to do so. They knew something “just wasn’t right”, and yet they did not know or understand what was wrong with their children or how to help them. They see their children’s many struggles and how their children need constant support, and yet they also recognize their children’s many gifts and talents. They struggle with the balance of trying to protect their children and yet knowing they must let go of some aspects of their children’s lives. They know they are doing all that they can to help their children and yet recognize that others may not see the same thing, may see them as “bad mothers” instead of women who are doing the best they can to mother their children. They are living with the guilt and shame of their child’s disability, and yet they are the ones who are always there, the ones who are always seeking something better for their child. Mothering a child with FASD for these women contained all of these incongruities, conflicting emotions which the women live with and live through in their journeys as birth mothers of children with FASD.

Reflections on Being a Birth Mother of a child with FASD

The four women who participated in this research taught me a great deal about the experience of being a birth mother of a child with FASD. The women’s stories were filled with reflections on their past. They live with their own past in a way that most people do not

experience; they are confronted with their past decisions both by themselves and by those around them. All four of these women have had to find ways to move beyond their past decisions to become the women that they are today. The guilt and shame that I was so curious about at the outset of this research was ever-present, ever-changing and for these women, weakening in intensity, but remaining in the women's lives to this day.

The women talked about living in relation to others in the community, how they have experienced both judgement and understanding, and how those reactions have impacted their journeys as birth mothers. The interactions of their own feelings of blame and the blame of those around them were evident throughout their stories. The women talked about feelings of worth throughout their lives of birth mothers, how they have struggled to be worthy in their own eyes and in the eyes of those around them since their early childhoods. Finally, the women told so many stories of mothering, of being mothers and struggling to mother their children through addictions and low self-worth.

All of these aspects of the women's experiences of being birth mothers of children with FASD are intrinsically related. The constant interaction between the reactions of those around them and the women's internal feelings of worth and shame were evident. The women's experiences of mothering were also intertwined with their emotional experiences of guilt, stigma and self worth. The themes discussed here are not separate entities, but rather a variety of emotional experiences that unite to form the experience of being a birth mother of a child with FASD. For these women, being a birth mother is all of these things: living with the past; living with the judgements of others; living with judgements of self and living with the conflicting feelings of mothering as a birth mother of a child with FASD.

Common throughout all of these interconnected themes is an ongoing journey, an ongoing healing which the women discuss in relation to all of these themes. This journey, this movement occurs throughout each aspect of the women's lives. These particular women's lives as birth mothers are defined by this movement towards worth, towards self-forgiveness and towards understanding. This healing in each area seems intrinsically related to each of the other areas. As the women found healing and forgiveness of self in relation to their guilt and shame, they also began to find self-forgiveness, find worth within themselves, find understanding in others and find worth in their experiences as mothers.

CHAPTER 5

DISCUSSION

This research project sought to answer the question: what is the essence of the experience of birth mothers of children with FASD since the birth of their child? In this chapter I will revisit the results in a discussion of the connections to the literature which is available on birth mothers of children with FASD and women who use substances during pregnancy. I will first discuss the context of the women's experiences, and how the four women's lives examined here are situated within the available research. Following that I will attempt to place each of the themes within the greater pool of research and offer recommendations based on the findings of this study.

Discussion of Demographics

Van Manen (1997) reminds us that in doing phenomenology we must search for a balance between individual stories and the overall essence of a human experience, between "the parts and the whole" (van Manen, 1990). He states that, "A powerful phenomenological text thrives on a certain irrevocable tension between what is unique and what is shared, between particular and transcendent meaning" (van Manen, 1997, p. 346). In balancing the part and the whole, in order to truly understand the essence of being a birth mother of a child with FASD, it is helpful to first understand the context, the life story of each woman. In attending to each individual story, we can gain insight into early life experiences and characteristics that are common and differing among the women and gain greater understanding of this experience.

What became clear in the individual stories of each of the women is that being a birth mother of a child with FASD does not simply happen; it is one part of a life story. The experiences after the birth of their children are intrinsically related to the earlier life experiences of the women. Although this study did not focus on the risk factors associated with becoming a birth mother, it does provide some perspective on the way the risk factors that are cited in the research are played out in the women's lives.

One characteristic that stands out as being present for all four of the women is the early experience of sexual abuse. All four of the women experienced either long-standing sexual abuse or a single sexual assault by the age of thirteen at the hands of family or trusted family friends. This corresponds to the statistical data available on birth mothers of children with FASD which states that over 95% of birth mothers were either physically or sexually abused (Astley et al., 2000b). The women in this study discussed using alcohol as a way to "hide" from the abuse, a

way to deal with the complex memories and emotions related to these past experiences. Sexual abuse has been found in research to be associated with a higher risk of alcohol and drug abuse later in life, as well as a higher risk of depression and suicide (Nelson et. al, 2002). Furthermore, early trauma impacts the ability of a child to manage emotions and develop healthy coping skills (Malchiodi, 2008), therefore alcohol and drugs are often used as a coping method later on in life. It has been suggested that many women who abuse alcohol will continue to relapse as they are unable to cope without the use of alcohol, unless abuse recovery is offered as part of addictions treatment (Astley et. al, 2008b). The current study is consistent with previous research in that the women used alcohol to cope; the women talked about how healing from the emotions related to abuse had to happen in order to stop using alcohol.

The current study has added to our understanding of how these past experiences are a part of the women's lives as birth mothers of children with FASD. Being a birth mother of a child with FASD was connected to the previous sexual abuse for these women; the healing of each was intertwined and the use of alcohol was closely connected to past experiences of abuse. Furthermore, feelings of being worthy and unworthy appeared to be closely connected to this past sexual abuse for the women, an association that is echoed in the literature (Kim & Williams, 2009). For these women, sexual abuse was one of the many life events that they described as contributing to the sense of being unworthy of love, an unworthy woman. Furthermore, healing from the sexual abuse was closely connected to developing a greater sense of self-worth, of being worthy.

A further connection that was shared among three of the women was the presence of alcoholism within their families of origin. The women talked about alcohol being a constant presence, about how their families used alcohol throughout their childhoods and about how it was easily available to them at a young age. This history of alcohol use and alcoholism in the family of origin relates to previous research with birth mothers. In her study of the lives of birth mothers in Alberta, Dorothy Badry found that alcoholism in the women's family of origin was an important part in the journey of "becoming" a birth mother (Badry, 2008). Quantitative studies have also found that birth mothers of children with FASD were more likely to have family histories of heavy drinking (May et. al, 2005; Vijoen et. al, 2002). Furthermore, this constant presence of alcohol in the early lives of the women may have contributed to the early age that the women started using alcohol and drugs, which is another risk factor for having a child with

FASD (Astley et. al, 2000b). An important learning that the women in this study have brought to the surface is the continuing impact that these early experiences with alcohol have in the women's lives as birth mothers of children with FASD. Early experiences with alcohol seemed to influence the way the women coped with emotions and became integrated into their ways of being. These relationships with alcohol continued throughout the women's lives as birth mothers.

The three First Nations women who participated in this study are all survivors of residential school. Residential school is a term used in Canada to describe the schools in which First Nations and Inuit children were placed in away from their families. Residential schools sought to assimilate First Nations children and to convert them to Christianity through the "denouncement of indigenous culture and language as inferior and immoral" (Tait, 2003, p. 206). Children in residential schools faced separation from family, a loss of culture and language and many were sexually abused by those who were entrusted to their care (Furniss, 1995). The impact of the residential school system was felt not only by individual survivors of residential school, but by entire generations of Aboriginal peoples, a consequence which is described as "collective intergenerational trauma", referring to the impact that these historical events have on present elevated rates of poverty, addictions and abuse among First Nations people in Canada (Tait, 2003). Some of the long-term psychological and social consequences which have been linked to the residential school system include high rates of alcoholism, suicide and sexual abuse, the loss of culture, low self-esteem and the loss of parenting skills (Furniss, 1995). Furthermore, there is an increasing "link between the 'residential school experience' and perceived high rates of FAS in Aboriginal communities" (Tait, 2003, p. 217). Residential schooling is connected to a variety of negative social outcomes for aboriginal peoples in Canada, however, its presence as a risk factor in becoming a birth mother of a child with FASD is often absent in the research. For the First Nations women interviewed in this study, it seemed to be a powerful part of the stories and journeys. The women's stories touched on this experience, further research in this area may deepen our understanding of the connection of residential school in the lives of birth mothers of children with FASD.

A further consistency from the participants' stories to the available literature is the characteristics of their pregnancies. Multiple pregnancies and stressful life situations during pregnancy have been cited as risk factors for having a child with FASD (Armstrong, 2005; May et. al, 2008; Viljoen et. al, 2002). The women who were interviewed had between three and six

children, and all four of the women were under the age of twenty at the time of their first pregnancy. It is suggested that high parity is associated with higher levels of FASD because of the characteristics of alcoholism; the longer a woman drinks heavily, the more severe the potential for medical complications for herself and the fetus (Abel & Hannigan, 1995). Furthermore, the women in this study also experienced periods of stress during their pregnancies. The women described their pregnancies as occurring in times of their life when they were under the most personal distress from past abuses and current life situations. Stress during pregnancy is cited as a risk factor that can increase the chances of a baby developing FASD (May et. al, 2008; May et. al, 2005; Viljoen et. al, 2002). A variety of psychological and physical stresses may exacerbate the negative effects that alcohol has on the developing brain (Abel & Hannigan, 1995). This research has added to the understanding of how women experience these periods of stress during their pregnancies and how that may impact their lives as birth mothers of children with FASD.

I would like to move beyond a simple comparison of the ways in which the women's lives correspond with the quantitative data available to discuss some important unique circumstances in the lives of the women. Although the profiles of birth mothers of children with FASD paint a picture of the "typical" birth mother, not every woman fits into that exact profile. Within this study I was fortunate to learn about the experiences of being a birth mother of a child with FASD from a variety of perspectives; from what would be considered the "typical" story, to women who represent other populations of birth mothers. I would therefore like to discuss the aspects of being a birth mother that Amanda and Ruth brought to this dialogue.

I find Amanda's experience extremely valuable to this study because she has brought the perspective of a woman who is outside of the "typical" in that she is part of a successful, middle class family, is Caucasian, and her family of origin did not abuse alcohol and drugs. Amanda does have similarities to the other women in that she experienced sexual abuse as a child and suffered with low self worth and inadequacy throughout her early life. Throughout her story, Amanda talks about how the trauma and abuse in her early life influenced her over-use of alcohol during the time of her pregnancy and early adulthood.

Amanda's daughter had many difficulties throughout her childhood and teenage years, to the point that Amanda was constantly seeking how to help her child. Not once during that time in her life was Amanda asked if she drank during pregnancy. In contrast, Lynn, living on a First Nation,

was asked by her child's school quite quickly if she had drank during pregnancy as her son displayed problematic behaviours. It has been suggested that one of the reasons that the rates of FASD are so much higher among Aboriginal populations and those living in poverty in Canada is that there may be a bias in the screening for FASD, that maybe women who do not appear to fit within the "typical" description of a woman who would drink during pregnancy are not asked this important question (Tait, 2003). Amanda's story corresponds with that point of view; if she had not pursued the assessment independently her daughter would continue to receive no supports for her disability and Amanda would likely continue to live in confusion and frustration with her daughter's difficulties.

To me, the most interesting aspect of Amanda's story is the fact that within all the many different life situations, there are many similarities. Amanda would not fit the "typical" description of a birth mother in that she is not currently in poverty, yet she did experience times of poverty around the time of her pregnancy. Although she was never involved with child protection, she recognized that she likely would have been if she had not had the support of her extended family when she was struggling to find her own worth. She has experienced the same love for her child, the same feelings of guilt and shame, and the same fears of judgement as the other women. Like the other women, she has also worked to come beyond her fears and her guilt, supporting and advocating for her child and others like her.

The second story which is outside the "typical" is that of Ruth. To me, Ruth represents those women who are on the furthest outskirts of society, those women who are usually very hard to reach in a research setting. Ruth's life as a birth mother of a child with FASD was filled with extreme marginalization, homelessness, domestic abuse, prostitution and drug addiction. The unique teachings brought by Ruth to this understanding of being a birth mother were the many ways in which someone in her situation is constantly failed by the "system". Her story as a birth mother is filled with times in which she felt let down, unsupported and unworthy of supports. Her children were taken from her and she felt alone and left to "wander" the streets.

I believe that one of the main important points in Ruth's story is that she states that her mother also drank when she was pregnant with Ruth. Although Ruth is not diagnosed with FASD, she talks about her many struggles with learning that are similar to her son's struggles, she talks about feeling "overwhelmed" with trying to pay bills and take care of her young children. From what I take from Ruth's story, it seems that she needed a great deal more support

than the support that was offered to her. I cannot assume that Ruth does or does not have FASD. However, if we consider Ruth's story in a larger sense of what we need to learn about FASD, a new line of research is needed: what are the experiences of mothering by individuals affected by FASD? What type of support do women who have FASD need to be able to effectively mother their children?

Even if we do not know if Ruth was affected by the alcohol that her mother drank while she was pregnant with Ruth, she has taught me a great deal about how women who are struggling with homelessness and severe addictions still desire to be a mother to their children. Through all of Ruth's struggles she thought about her children, grieved for her children, felt shamed about the loss of her children to government care. Ruth has also managed to come out of that life and move to a healthier place.

Being a Birth Mother: Discussion of the Main Themes

The themes in this research project were related to the women's emotional journeys in being a birth mother of a child with FASD. In this section I will connect these themes to the larger body of literature and discuss what each of the themes has added to the understanding of birth mothers of children with FASD.

Living with the Past: Connections to the Research on Guilt and Shame

Consistent with the limited research available on birth mothers' experiences (Badry, 2008; J. Salmon, 2008), the women in this study discussed guilt and shame as an integral part of this experience of being a birth mother of a child with FASD. For these women, guilt and shame were ever-present emotions that they had healed from, moved beyond and yet often remained in their lives to some extent. These emotions were all encompassing for the women, connecting to other events in their lives and impacting multiple areas of their present and past experiences and relationships. These experiences are in line with the research which discusses the many negative implications of living with guilt and shame on the lives of individuals.

The research into the emotions of guilt and shame imply that both guilt and shame can have negative impacts on an individual life (Silfver, 2007). However, guilt is seen generally as an emotion which motivates individuals to make reparations to the harm they have caused, since the emotion is focused on the negative action which they have taken (Schmader & Lickel, 2006). Shame is conceptualized as an emotion in which the individual focuses on the self, rather than the action, thus resulting in avoidance behaviours, isolation and a focus on themselves as a "bad

person” (Hooge et. al, 2007; Schmader & Lickel, 2006). Both of these emotions are labelled by the women and we can see these differing reactions and behaviours in the women’s subsequent relationships with themselves and others.

The motivation to make reparations that is often associated with the emotion of guilt is seen in the women’s relationships with their children. The women told stories of apologizing to their children for their use of alcohol or drugs during pregnancy. Furthermore, some women talked about how their constant support of their children was sometimes a form of “owing” their child because of the consequences of drinking during pregnancy. Although Amanda did talk about this “owing” as being a positive experience, something she could do to help her daughter, Irene talked about how she tried to do everything for her children because she “owed” them, because she felt so much guilt.

One theory suggests that if individuals are not able to repair damages to the victim, they may engage in self-punishing behaviours (Nelissen & Zeelenberg, 2009). Although we see that birth mothers do apologize to their children and support them throughout their lives, the women also know that the effects of their drinking are permanent. This causes tremendous grief, and the women did talk about self-punishment along with their guilt. They talk about wanting to punish themselves, about expecting and wanting that punishment from others around them. This also seems related to further feelings of being unworthy for the women, feelings of “deserving” painful life events.

Although guilt has been found to have negative impacts on an individual’s life, shame has been conceptualized as the more maladaptive of the two emotions, as individuals evaluate an action that they have committed and apply it to their opinion of themselves (Dost & Yagmurlu, 2008). Individuals experiencing shame have been described as feeling small and worthless, as devaluing their entire self based on a previous action (Silfver, 2007). The women talk about this self devaluation throughout their stories, discussing how each step of the way throughout their early journeys as birth mothers they felt unworthy, how they hated themselves and couldn’t even look in the mirror. The women’s experiences of shame were strongly connected to their experiences of being unworthy. Furthermore, as the women began to heal from the shame, they also began to experience moments of worth, began to find worth in themselves and in their lives as mothers.

Guilt, shame and feminist theory. The women discussed guilt and shame in their lives not only from drinking during pregnancy, but also from a variety of other life events and choices they had made. Feminist research discusses how women's choices and behaviours do not occur in isolation, but rather as part of the society in which they reside (Marcellus, 2007). Women living in poverty are required to make a variety of choices in order to survive and often in order to care for their children. The combined trauma of these events serves to further isolate women and push them into even further traumatic lifestyles. By discussing drinking alcohol during pregnancy as an individual "choice" which is 100% preventable, we forget the complicated lives which women live (Tait, 2003). For the women who participated in this study, the connection between the use of alcohol and previous traumas and life situations was mentioned repeatedly throughout the interviews. The women discussed guilt and shame not only for drinking during pregnancy, but also for many other decisions made living in lives of poverty and abuse.

Schellenburg (2007) describes how society labels women as the individual cause of FASD in order to move the attention away from the societal responsibilities to those living in poverty. The guilt and shame experienced by the women in this study were deeply rooted in the limited life choices that were available to them in their situations. Furthermore, that guilt and shame for individual actions occurred within a society that did not offer them the support or opportunity for alternate choices.

By ignoring societal impacts on behaviours, a situation is created in which individual guilt can worsen already damaging addictions. Research tells us that when women have several children with FASD, often the younger children are more severely affected than the older children (Astley et. al, 2008a). There are several reasons that this may be. One possibility that appears to be supported by the stories of the women I spoke to is the idea that the lack of support in dealing with addictions and the blame that is placed upon women for their child's disabilities contribute to the worsening of addictions over time. By the time that younger children are born, addictions are out of control and women have no supports to deal with them. The emotions of guilt and shame are both linked with personal distress and problematic alcohol and drug use (Dost & Yagmurlu, 2008) and internalized shame can lead to an increase in drinking (Eliason, 1995). A cycle can easily be created of drug and alcohol abuse, guilt over the consequences of that use, and then further alcohol and drug abuse used to cope with those emotions.

Healing. I was personally interested in the stories of healing that came out in all of the women's stories. Despite the descriptions of the power that guilt and shame held over them in the beginning of their journeys, the women all discussed how they had managed to heal, manage to control the guilt and shame to come to a place of greater purpose in life. The term "healing" implies more than simply coping, not only dealing with an issue, but the possibility of personal transformation and transcendence (Gockel, 2009). This process of change and transcendence for the birth mothers is seen in the positive changes they have made as a part of their healing. The women interviewed here all talked about great change that has occurred in their way of life, and also their attitudes about life and about themselves. They moved from places of feeling unworthy, unfit and unloved to feeling that they had a purpose, a passion for life.

All four women discussed some form of spirituality as being an important part of healing from the guilt and shame of being a birth mother. Spirituality and cultural activities are cited as an important part of healing for many people, surveys have found that from 70-90% of people with serious mental and physical health problems use spirituality as a form of coping (Gockel, 2009). The importance of this connection implies the need for the integration of spiritual activities into addictions treatment where desired by women who abuse substances.

The women also talked about how the support of others helped the women in their journey of healing. For these women, who expected the judgements of others, and who so severely blamed themselves, reactions of understanding from others seemed to be pivotal points in their journeys of healing. This finding is consistent with research which states that social support is important for individuals from stigmatized groups in society (Kelsey, 2004). The women in this study have provided some important pieces to our understanding of healing and self-forgiveness for birth mothers of children with FASD.

Living with Others: Birth Mothers in Society

The next theme in this research was related to the women's experiences in relation to those around them and those individuals' reactions of either blame or understanding. The most impactful aspect of the stories of blame for me was in the women's judgements of self and their expectations that others will judge. The women were aware of attitudes of the general public towards birth mothers of children with FASD and spoke of a fear of judgement, an anticipation that their stories would be met with blame. This fear impacted the women's ability to speak out about FASD, as well as the ability to seek supports for their child and to seek supports while

pregnant. Furthermore, this fear impacted the women's concepts of self and ability to talk to others about their circumstances.

Research on supports for women who are pregnant and using substances discusses this connection between fear of judgement and the ability to access supports. Women state that fear of losing their children is one of the most prominent reasons that they avoid seeking supports for alcohol use during pregnancy (Astley et. al, 2008b; Poole & Issac, 2001). This fear is not unsubstantiated. As was experienced by Ruth at the birth of her last child, it is common in Canada for children to be taken away at birth from women who use substances during pregnancy (Boyd, 2007a). The women who participated in this study received messages of being "bad mothers" and being unfit to mother from themselves, from their experiences with child protection services and from those around them.

What becomes clear is that the impact of societal judgement and blame is not greatest in the daily lives of the women in experiences of external stigma but rather the internalization of that stigma. For these women, stigma was internalized and integrated into their conceptions of self and their place in society. This internalization can also be related back to the women's experiences of shame. The definition of shame is an evaluation of the self based upon an internalization of moral standards that is characterized by avoidance behaviours (Dost & Yagmurlu, 2008; Schmader & Lickel, 2006). Perhaps the judgement of others is most impactful in its influence on the women's evaluation of themselves and ability to seek the support of others.

Although the women experienced blame and also feared or avoided the blame of others, at times they were also met with understanding and compassion. There appeared to be a connection between supportive responses and the ability of the women to heal from guilt and shame, to move towards self-forgiveness. All of the women identified that talking to supportive people assisted in their healing process. Lynn and Irene discussed family members; Ruth described a non-judgemental addictions worker; Amanda described a support network of parents she belongs to. Kelsey (2004) discusses how being part of a stigmatized group can lead to an internalization of stigma and the loss of social support (Kelsey, 2004). Individuals who live with shame are isolated from others because of that shame, and empathetic responses from others can contribute to healing (Kelsey, 2004). Furthermore, in empathizing with others' who have experienced similar shame, individuals are more able to accept themselves (Kelsey, 2004).

Shame is an emotion which creates a sense in an individual that they are unlovable, unworthy and that there is no hope in receiving empathy from others (Jordan, 2001). By reacting with compassion and support, others can contradict this feeling of unworthiness and assist the women in their path to healing. Jordan (2001) suggests that in order to heal from shame, individuals must experience connections to others. She states,

To heal shame, the person suffering with shame must come to believe that another person can respond empathically to his or her experience. The shamed person must come to see that he or she is respected, that he or she matters, that the shamed parts are also empathically responded to by the other person (Jordan, 2001, p. 100-101).

This connection between internal shame and empathetic reactions of others has important implications for those working with birth mothers of children with FASD, and with mothers or pregnant women who use substances. Three of the women who participated in this study had several unsuccessful attempts at addictions treatment before they managed to successfully maintain sobriety. The women talked about how supportive responses from others assisted their journey of healing, and how support workers without judgement assisted them to admit the times when they “fell” and return to treatment. The women talked about a feeling of belonging and understanding from others as important parts of their journeys to self-forgiveness. These results suggest that those working with birth mothers of children with FASD may be able to assist the women on their journeys through offering non-judgemental and empathetic support to the women.

Mothering as a Birth Mother of a Child with FASD

Research has been available on the experiences of caring for a child with FASD, but this study has helped us to understand the experience of care-giving through the eyes of birth mothers of children with FASD in particular. One learning regarding the women’s experiences of mothering is that some of the stories of mothering echoed much of the research on caregivers of children with FASD in general. The women experienced frustration, confusion and a constant seeking of supports. They continue to parent and guide their children well into adulthood. As part of being a birth mother of a child with FASD, these women faced the constant difficulties of their children on a daily basis. The women described behaviours and characteristics of their children that closely matched those described in the research on individuals with FASD. The

women described their children as facing unique challenges from the period of infancy to adulthood. The difficulties described by the women are not uncommon for children and adults living with FASD, in fact they closely match those discussed in the research as the common “primary” and “secondary” disabilities associated with FASD (Streissguth et. al, 1997). What this study has brought to the research is a greater understanding of how birth mothers of children with FASD live with these difficult behaviours.

As mothers, these women were the ones who were always there, who supported their children through all of the difficulties mentioned above. The few studies of the experiences of caregivers of children with FASD contain themes related to their children’s disabilities and the support they must give them on a daily basis (Clement-Murphy, 2001; Garder, 2000; Gammon, 2000). Just like those caregivers, the birth mothers’ stories were filled with descriptions of their child’s difficulties, and how always trying to cope with the frustration of their child’s behaviours.

There are further connections to the experiences of caregivers of children with FASD. Caregivers of children with FASD describe how they have to help others understand their child’s disability (Clement-Murphy, 2001). The birth mothers here were seen to be always seeking, always advocating that their children receive the supports that they need. Caregivers have also noted the need to see their child as an individual, not simply as another child with FASD (Brown & Bednar, 2003). The women interviewed in this study echoed that sentiment, but took it one step further. They stressed the need to see their children as individuals, but also as individuals with a variety of gifts and talents, not just with disabilities.

One interesting aspect that was common between these mothers and the adoptive mothers of children with FASD was the experience of being blamed or blaming oneself for the child’s difficult behaviours. Even before Amanda knew her child had FASD, she was blamed for her child’s behaviours, seen as a “bad mother” to those around her because she couldn’t control her child. Similarly, foster and adoptive mothers of children with FASD have talked about how they felt they could not live up to the myth of the “ideal” mother when raising their child with FASD, and how they would feel guilt, feel like they had failed their child when their child experienced the many difficulties of living with FASD (Gammon, 2000).

These commonalities in the experiences of mothering between the birth mothers and studies with adoptive and foster parents are interesting to me for several reasons. First, they reaffirm the need for individuals caring for children with FASD to be provided the level of support needed to

care for their children. Second, birth mothers of children with FASD are depicted in our society as “bad mothers” and these women have seen themselves as bad mothers as well. Children of women who use substances during pregnancy are often apprehended at birth under the assumption that the woman will be unable to care for them, that she is unfit to be a mother. Contrary to this common assumption, these mothers’ experiences as mothers are in many ways just like any other caregiver of a child with FASD. They are “always there”: through the tantrums and the break-ins, through the falls and the triumphs, these women were mothers to their children, were “good mothers” in every way they could be. However, there were also components of the women’s stories of mothering that are distinguished from other caregivers, that situate these women within the unique experience of being birth mothers of children with FASD.

A part of what sets the experience of being a birth mother of a child with FASD apart from the experiences of foster and adoptive mothers is that the women continued to have difficulty coping and feeling worthy throughout their children’s lives. The women in this study discussed the use of alcohol as a way to cope with emotions and past experiences. It is therefore not surprising that the women had continued issues with the use of alcohol after the birth of their children. Parenting a child with FASD involves a variety of challenges related to the child’s disability, and higher levels of behavioural problems among children with FASD are related to higher levels of parental stress (Paley et al., 2006; Paley, O'Connor, Kogan, & Findlay, 2005). Caregivers of children with FASD recognize that their children’s disabilities are difficult to cope with on a daily basis and that coping skills are necessary to parent a child with FASD (Gardner, 2000). For the women in this study, alcohol was a coping method developed over time that they continued to use as they mothered their children. As stress levels increased, alcohol continued to be a way to deal with that stress.

Coping skills have been defined as “...conscious volitional efforts to regulate emotion, cognition, behaviour, physiology and the environment in response to stressful events or circumstances” (Wadsworth & Compas, 2002). Coping skills have been divided into both active and avoidant categories (Holahan & Moss, 1987). Active coping skills include strategies to confront and deal with the problem. They can include cognitive strategies such as looking at the positive side, or behavioural strategies such as problem solving or exercising. These active coping skills are found to be associated with positive psychological outcomes. Avoidant coping

strategies, on the other hand, are associated with more psychological distress and include things like keeping feelings to oneself or reducing tension through drinking/eating/ or smoking more (Holahan & Moss, 1987). Today these coping skills are often referred to as “helpful and unhelpful” (Lauver, Connolly-Nelson & Vang, 2007).

The women who participated in this study discussed using alcohol as a way to avoid emotions from early adolescence. In order to cope with the difficult emotions associated with mothering a child with FASD, as well as the emotions related to feelings of being unworthy and unfit, the women continued those same coping patterns of using alcohol. The women’s stories of mothering were often tied to their stories of coping through the use of alcohol and drugs, and with mothering through these psychological problems. Furthermore, within their stories of healing, all four of the women discussed more helpful coping skills which they developed to replace the use of alcohol, such as prayer, talking to others, cultural activities and meditation. The results of this study suggest that holistic addictions treatment which assists women in developing new styles of coping may be helpful for birth mothers of children with FASD.

Being Worthy

This aspect of being a birth mother of a child with FASD was the most meaningful to me, the hardest aspect to pull out of the women’s stories, but the most enlightening in my eyes of what it is to be a birth mother of a child with FASD. These four women were pushed aside and devalued all of their lives, abused, neglected, isolated and abandoned. The women were thus left feeling unworthy, unvalued and unloved, both before and after the birth of their children. The use of substances for these women was often one of many consequences of this low self worth, this feeling of being not valued in the society which they live. Not only did the women experience being unworthy as human beings, but also unworthy of the basic knowledge about the harms of drinking during pregnancy, an aspect of their lives which seemed to me to be the ultimate expression of being devalued in our society.

There are interconnections of these feelings of low self-worth to many aspects of the women’s lives. The women talk about the feelings of being unworthy in relation to past abuse, in that it lowered their opinion of themselves. For example, Amanda discussed feeling that she was “just there to be used.” The women also talk about feeling unworthy in the eyes of support workers as Ruth mentioned that she felt like she was being told she didn’t “deserve” any support. Finally, being birth mothers of children with FASD, the women talked about how they felt a low

sense of self worth after gaining knowledge about the harms of drinking during pregnancy. Thus these feelings of being unworthy permeated all areas of the women's lives, and were the result of messages about multiple aspects of the self.

Research on self-worth shows connections between low self-worth and experiences of child abuse (Kim & Williams, 2009), between self worth and feelings of shame (Jordan, 2001) and between low self worth and the judgements of others (Gamble & Yi, 2008). Looking at the birth mother's lives as a whole, feelings of being unworthy are a part of their early experiences and a part of the life in which they currently inhabit, being a birth mother of a child with FASD.

Recognizing the social context in which birth mothers of children with FASD live, it helps to see self-worth from a relational perspective. Recent literature discusses the ways in which individuals integrate others' perceptions of them into their concepts of self. This interpersonal concept of self is labelled as the "relational self" (Anderson & Chen, 2002; Hoberg & Chen, 2010). The theory of the relational self assumes that our concept of self is "entangled" in our relationships with the significant others in our lives; that our self concept has multiple aspects and each aspect is intrinsically related to aspects of our significant others (Anderson & Chen, 2002). In this theory, significant others represent all of those individuals whom we are close to in throughout our lifetimes, including both family and friends. Self concept is then related to whether one considers herself to be meeting or failing the expectations of these significant others (Anderson & Chen, 2002; Hoberg & Chen, 2010).

This relational theory of the self provides assistance in understanding the birth mothers' experiences of being unworthy. From their early lives they had received messages that they were "failing" in the eyes of those closest to them through experiences of abuse, early pregnancies and addiction. Continuing on through their lives, they became mothers of children with FASD, one of the most stigmatized groups in society. They recognized the stigma and shame associated with their positions in their communities and internalized those emotions into their concept of self. The stories of judgement and blame from the women's own children seemed the most hurtful to the women themselves, these children are some of the most significant people in the women's lives; seeing themselves as "failing" their children contributed to further feelings of being unworthy.

Theories of the relational self also recognize that individuals place different amounts of emphasis on success in different areas of their lives in their formations of self-concept (Hoberg

& Chen, 2002). For example, some individuals may place great emphasis on being successful in school and others on being attractive. What elements of life that individuals choose to integrate most deeply into their concepts of self seem to be related to what they perceive to be most important to the significant others in their lives (Horberg & Chen, 2002). Perhaps the most meaningful part of many women's lives, the part of their lives that they most wish to be successful and a part of their life which they integrate intensely into their concepts of self, is the experience of being a mother. These women were no different, Amanda talked about how she was "just a mother" through periods of her life, how that role became the only role in her life. Lynn talked about the messages she received from significant others early in life to always "take care of your children."

Considering the level of importance that being a mother seemed to hold within the women's concept of self, it is not surprising that the women felt "worthless" when they had experiences of being unfit to mother, of being unworthy of being a mother. To me, as a woman, being a mother seems a biological birth right, an important experience which is hard to separate from being a woman. Women all over the world receive messages about the importance of being mothers, of how to be "good" mothers. These women received messages that they were not good mothers. That it was important to be good mothers, but that they were "bad" mothers. They were told they were unfit to mother by child protection services, by those closest to them and by themselves. As such an important part of the self, these women began to see themselves as unworthy of being mothers, unworthy of being women, unworthy of being.

Using theories of the relational self can also help to understand the healing that the women have come through in becoming worthy. The women have all discussed their healing in terms of finding purpose in relation to others. Lynn talks about how her kids see her as a "supermom" and how she feels that she has a greater "purpose" to support individuals with FASD. Ruth talks about how becoming a Kokum was a step towards healing from the use of alcohol for her, she became someone worthy of healing through the relationship with her grandchild. Through their relationships with those around them the women have moved along in their journeys towards worth. By finding places within their lives in which they are successful, by discovering personal value through spiritual and cultural beliefs and by finding a greater purpose to being a birth mother of a child with FASD, these women have begun to move from "unworthy of being" to "being worthy."

The Journey Continues

The journey will go on for these women, for their children and for many others like them. Within the women's stories are several clues as to some of the research, intervention and prevention efforts that could be helpful for birth mothers and their children.

A Small Piece of the Story: Limitations

The four women who participated in this study represent a very small piece of the story of being a birth mother of a child with FASD. Their experiences offer another piece of understanding, a tiny glimpse into the essence of being a birth mother of a child with FASD. By learning from them we can gain greater understanding of this human experience, but within the unique context of these women's life stories. The four women interviewed here were unique in the fact that they had experienced long journeys of healing prior to entering into the research. They had experienced times of severe addictions and of deep emotional pain; however they had travelled long roads to be able to speak about overcoming these obstacles in their lives. This type of experience is extremely valuable to learn from, however it may essentially different from the experiences of those women are still struggling on a daily basis to simply get by as birth mothers of children with FASD. This research thus only represents one piece of the puzzle; other women have many other teachings of what it is to be a birth mother of a child with FASD.

This research was also limited to women who are involved in the parenting of the child with FASD. Unfortunately, a small percentage of children with FASD actually live with their birth families for significant periods of their lives (Clement-Murphy, 2001). The majority of birth mothers of children with FASD are living with their children in foster care or in adoptive care. These women again represent a very different perspective and different line of research than the women interviewed here. Living as a birth mother without your children may involve a very different emotional experience when compared to mothering as a birth mother.

Worthy of Support

Much of the research of birth mothers of children with FASD focuses on prevention of FASD. Of course that line of research is extremely valuable; efforts to stop or reduce drinking during pregnancy will help support women to have healthy pregnancies and reduce the numbers of individuals in our community living with FASD. However, despite all of these prevention efforts, as long as women continue to use alcohol as ways to cope with marginalization, low self-worth and abuse, FASD will continue to occur. This research suggests that continuing supports

throughout as birth mothers of children with FASD mother their children may lead to better outcomes for both women and their children.

Supports that have been cited in the literature as needed by caregivers of children with FASD, include the support of family and friends; professional resources; collaboration with the school; health and social services; the need to see the child as an individual; child management skills; and personality characteristics such as humour and patience (Brown & Bendar, 2003). The results of this research suggest that similar supports may be needed by birth mothers of children with FASD who are raising their children.

However, considering the impact of alcohol in these women's lives, very different and specialized supports may also be needed by birth mothers of children with FASD. The challenge of raising a child with a disability is great for any mother; however, it is even greater if the mother has to deal with alcohol and drug addictions while mothering (Arendt & Farkas, 2007). The women's stories were filled with times where they were struggling to mother, to be the perfect mother, a "good" mother, while at the same time they were "not doing very good." Furthermore, the women experienced social stigma related to drinking during pregnancy and internalized feelings of guilt, shame and unworthiness. These psychological experiences and addictions present barriers to parenting for the women. The women's experiences suggest that birth mothers of children with FASD need a variety of specialized supports depending on their individual situation in terms of healing from addiction and psychological well-being. Non-judgemental and comprehensive supports may provide better outcomes for both women and their children (Boyd, 2007a, 2007b).

In providing support for women, outcomes for their children may improve in as far as the women will be better able to provide secure and nurturing care for their children in their own homes. To further support women and their children the process of diagnosis of FASD can also be considered in relation to the women's experiences. The women who participated in this study who had accessed assessment services for their children all did so after long periods of healing, after no longer using alcohol, after a lot of dealing with the guilt and shame. Early diagnosis is the second protective factor which has been found to improve outcomes for children and adults with FASD (Streissguth et al., 2004). None of these mothers were able to access diagnosis for their children early in their children's lives. The diagnostic process for FASD in Canada currently requires confirmation of maternal alcohol use during pregnancy; this is usually

obtained through questioning the mother. The women talked about how understanding reactions of others assisted them on their paths to healing, indicating a need for non-judgemental and sensitive questioning throughout the process of diagnosis.

Although this study was not centred on the prevention of FASD, several interesting implications came out of the women's stories in relation to the current discourse on the prevention of substance use in pregnancy. There seem to be two opposing views on this topic in the research. The first discourse centres on the prevention of FASD through public education and the controlling of women's behaviours through the justice system. Followers of this philosophy believe that FASD is 100% preventable, that through education and punitive measures women will stop drinking during pregnancy (i.e. Szabo, 2000). This argument is refuted by the second common discourse, that education and retributive actions are not all that is needed to prevent FASD. These individuals argue that FASD not a simple consequence of one woman's choices, but rather the result of a complex web of societal interactions that leave some women in situations with few choices available to them. They argue that public education is only one step, and that substance use during pregnancy must be viewed within these complex social and political situations in which women live (Badry, 2008; Marcellus, 2007; Schellenberg, 2007).

The women in this research gave a variety of insights into both of these views in their lives. Two of the women's pregnancies occurred in the 1970s, before large public awareness about the risks of drinking during pregnancy. Those women expressed time and time again that they didn't know, that maybe it could have been different. For those women, public health education was an important missing piece, something which may have impacted their drinking throughout their pregnancies. For them, knowledge could have been a first step toward healthier pregnancies.

The opposing view, that public education is not enough, and that punitive approaches prevent women from accessing supports, is also substantiated by these women's experiences. Two of the women were aware of the harms which may occur from drinking during pregnancy; one woman drank a great deal in her early pregnancy and another was not able to stop using. The women's stories suggest that prevention is needed on many levels, from education and awareness to substance use treatment and harm-reduction. The need for both levels of prevention is reflected in the current Canadian policy on FASD prevention. The Public Health Agency of Canada currently describes four levels of prevention in Canada related to drinking during pregnancy; the first two levels of support are related to increasing awareness of the harms of

drinking during pregnancy, where the second two levels focus on assisting women to stop drinking during the prenatal and postnatal period, (Public Health Agency of Canada, 2008).

Mothers who have substance abuse issues who receive home visitation supports based on the needs of the individual as opposed to direct alcohol and drug treatment have been shown to be effective in improving outcomes for both women and their children (Ernst, Grant, Streissguth & Sampson, 1999). These integrated supports of multiple services in one setting have been shown to be most effective with women with substance use issues (Niccols & Sword, 2005). The women interviewed within this study all talked about healing from addictions as part of a greater healing in their lives, closely intertwined with healing from other abuses and traumas. Unfortunately, a recent survey of addictions treatment programs throughout Canada showed that approximately half of the addictions agencies in Canada do not provide integrated services (Niccols et. al, 2010). This research indicates a need for a focus on non-judgemental and holistic programming for women throughout their pregnancies and beyond.

New Directions: Recommendations for Further Research

Research has shown that guilt and shame can have negative psychological consequences (Dost & Yagmurulu, 2008) and the women's stories illuminate how these consequences impacted their emotional health, their ability to parent and their ability to maintain sobriety. How these four women have come to places of healing to the point where they can speak about guilt and shame openly, is an incredibly important aspect of this experience that calls for further research. This research has pointed to the importance of finding a sense of worth and self-forgiveness in the women's journeys of healing. Considering the many negative consequences that guilt and shame has been shown to have in the lives of the women, the more we understand about the journeys that women take towards healing, the better we can provide helpful environments and services to support their journey.

The experiences of the four women who participated in this study are consistent with the research on barriers to treatment for women who abuse substances. The women had trouble accessing supports that were meaningful to them, had trouble accessing treatment while mothering young children, and worried that their children would be taken away if they admitted their substance use issues. Furthermore, the women recognized the complex interconnections between their use of alcohol and other psychological traumas in their lives. Programs for women with substance use issues that recognize the multiple sources of women's substance use issues

and provide multiple services in one site have been shown to have greater impacts for women and their children (Niccols & Sword, 2005). More research is needed into how to most effectively manage barriers to treatment and provide integrated services for women with substance use issues.

As mentioned, the women studied here were part of a specific group of birth mothers. They were parenting their children for most of their children's lives and had gone through journeys of healing before entering this research. More research is needed with birth mothers of children with FASD in different situations. For example, Ruth was a woman who lived large portions of her life as a birth mother struggling with homelessness and severe drug addiction. Her experience was very different from the other women's experiences and more research is needed with others like her, those who are in the furthest marginalized corners of our society, those who are the hardest to reach, the most silenced of this already silenced group of women. Additionally, Amanda also represented a group of birth mothers which are often ignored in research. She is outside the "typical" in that she presents as a middle-class woman who would not be classified as an alcoholic. More research is needed into the unique situation of women who do not fit into that "typical" description of birth mothers of children with FASD.

The process of diagnosis happened very late in the lives of the children of these women. The women had all gone through significant healing before the process of diagnosis. Diagnosis was then mainly a positive experience for the women; they expressed feeling relief in having the assessment and interest in hearing their child's strengths and areas of difficulty. More research is needed into the barriers of accessing assessment and diagnosis earlier for these women and their children. What prevents women from accessing diagnosis for their children and what can be done to support them through the process? Furthermore, what is the experience of diagnosis and assessment like for birth mothers who are earlier on in their journeys, who are still very much living with guilt and shame on a daily basis? The basis of research on the lives of birth mothers of children with FASD is only beginning; we have much to learn in how best to support these women and their children.

Final Reflections: Continuing Ambiguity

In our society, with its focus on individualism and adversarial relationships, it is often difficult to reconcile two very different ways of thinking, to bring two opposing thoughts into one comprehensive understanding. However, when thinking about birth mothers of children with

FASD we are always faced with this conflict, this ambiguity. These women love their children; it is there in their stories, their smiles, and their pride. However, they all harmed their children during their pregnancies and have all struggled with mothering their children at some point in their lives. It becomes easy for society to say “how could you do that to your children?” and to assume that they must not be good mothers, must be unfit. But that is the easy explanation, the simple answer, the naive response. Women who use alcohol during pregnancy have lives filled with these contradictions, and this study suggests a need to move beyond this simple blame.

I would like to comment that removing blame does not equate to suggesting that it is recommendable for women to drink during pregnancy. It does suggest that in order for birth mothers of children with FASD to heal and to mother their children, they need to move beyond the internalization of blame and the experience of shame, which have devastating consequences for the women, their children and families. As a society, if we continue to focus on who to blame, we will also continue to ignore the supports that are needed by women and their children during and after pregnancy.

On a related thought, presenting birth mothers of children with FASD as capable mothers, as resilient and strong, does not suggest that these women do not need support and understanding in order to mother their children. These women faced real barriers to mothering throughout their lives, barriers related to addictions, low self worth and psychological trauma. In order to support both the women and their children, we need to again recognize two seemingly opposing thoughts: that these women are capable of mothering but that yes, they often need support.

I began this journey of learning about birth mothers of children with FASD in my work with the FASD Support Network of Saskatchewan. It seems fitting to come full circle and end with some thoughts on a quotation from that organization: “No one harms their baby on purpose.” The women who I spent several hours talking to re-confirmed this statement for me and strengthened my resolve to continue to advocate for these women who are so judged and so misunderstood in society. Women who drink alcohol or use other substances during pregnancy are presented as “bad mothers”, as women who are unable to care for their children, as women who do not love their children. Yet their stories show the opposite is true, that they love their children, that despite hardships and times of struggling to be healthy, they are powerful advocates for themselves and their children. They have also taught me that support provided throughout the lifetime could improve outcomes for women and their children. It is my hope that further

research will assist in moving away from the rhetoric of shame and blame to recognize the wisdom and insight which women are able to bring to policy and intervention planning for both women for individuals with FASD.

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APPENDIX A
RECRUITMENT LETTER #1



Are you the birth mother of a child with FASD?

Would you like to have a place to share your experiences and story in a private and safe setting?

If so, you are invited to participate in our upcoming research study.

Under the supervision of Dr. Laurie Hellsten, I am a Master's of School and Counselling Psychology student at the University of Saskatchewan. **I am exploring the experiences of birth mothers of children with FASD since the birth of their child.** I am seeking volunteers to participate in this research study and share their experiences.

Participation in this study requires:

- a) Two separate 1-2 hour interviews in a private setting regarding your experiences, emotions and ideas about being a birth mother of a child with FASD.
- b) A third 1-2 hour long interview in which you and the researcher discuss the common experiences of birth mothers of children with FASD.
- c) Reviewing the interview transcripts to ensure your experiences were correctly recorded and interpreted.

To participate in this study you must:

- a) Be a birth mother of a child or children diagnosed with FASD
- b) Living in Saskatoon and area
- c) Be 18 years of age or older
- d) Be currently involved in the parenting of the child with FASD
- e) Be willing and able to tell your story

If you are interested in learning more about this study, please contact Megan Wood at 717-0936 or mew345@mail.usask.ca and more details will be provided.

APPENDIX B
RECRUITMENT LETTER #2

Are you the birth mother of a child with FASD?

Would you like to have a place to share your story in a private and safe setting?

If so, you are invited to participate in our upcoming research study.



Under the supervision of Dr. Laurie Hellsten, I am a Master's of School and Counselling Psychology student at the University of Saskatchewan. **I am exploring the experiences of birth mothers of children with FASD since the birth of their child.** I am seeking volunteers to participate in this research study and share their experiences.

Participation in this study requires *about 3-5 hours* of your time:

- a) Two separate 1-2 hour interviews regarding your experiences of being a birth mother of a child with FASD
- b) A third 1-2 hour long interview in which you and the researcher discuss the common experiences of birth mothers of children with FASD
- c) Reviewing the interview transcripts to ensure your experiences were correctly recorded and interpreted

To participate in this study you must:

- a) Be a birth mother of a child or children diagnosed with FASD
- b) Living in Saskatoon and surrounding area
- c) Be 18 years of age or older
- d) Be currently involved in the parenting of the child with FASD
- e) Be willing and able to tell your story

If you are interested in learning more about this study, please contact Megan Wood at 717-0936 or mew345@mail.usask.ca

APPENDIX C
RECRUITMENT LETTER #3

Are you the birth mother of a child with FASD?

**Would you like to share your story
in a private and safe setting?**

**If so, you are invited to participate
in our upcoming research study.**



Under the supervision of Dr. Laurie Hellsten, I am a Master's of School and Counselling Psychology student at the University of Saskatchewan. **I am exploring the experiences of birth mothers of children with FASD since the birth of their child.** I am seeking volunteers to participate in this research study and share their experiences.

Participation in this study will involve 3 one-on-one interviews,
approximately 1 – 1.5 hours per session

You will be reimbursed \$50 per interview

To participate in this study you must be:

- a) The birth mother of a child or children diagnosed with FASD
- b) Living in Saskatchewan
- c) 18 years of age or older
- d) Currently involved with the parenting of the child with FASD
- e) Willing and able to tell your story

If you, or someone you know, may be interested in participating,
please contact Megan Wood at 306-717-0936 or mew345@mail.usask.ca

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APPENDIX D
SCRIPT SNOWBALL SAMPLING

Hello, I am calling to let you know about a research opportunity that I recently heard about that I thought you might be interested in.

The research is being carried out for a master's thesis at the University of Saskatchewan, and is about the experiences of birth mothers of children with FASD. The researcher is looking for women who have a child with a diagnosis of FASD, who are in Saskatchewan, are over 18, parenting their child and are willing and able to tell their story. I thought that this might fit for you so I wanted to pass it on.

The research would involve three one-on-one interviews with the researcher. You would be paid \$50 for each interview.

There is no pressure for you to participate in this research and in no way does your decision affect your relationship with myself or the support you receive from our agency.

Do you think this is something you would be interested in?

If yes... Could I provide the researcher with your contact information so she can call you to discuss possible participation in the study?

If no... Ok, that's fine. Thanks for your time.

APPENDIX E
SCRIPT RESEARCHER INITIAL CONTACT

Hello, my name is Megan Wood, I am a master's student at the University of Saskatchewan. I understand that _____(name) from _____ (agency) has discussed with you the possibility of participating in my research study. She mentioned that you may be interested in participating. Is this a good time to talk?

If no... Would you like me to call back at a different time?

If yes... First of all I would like to remind you that you do not have to participate. I will give you a bit more information about the study, and you can let me know if you would like to be a part of it or not.

- The study is about the experiences of birth mothers of children with FASD since the birth of their child
- If you participate, there would be three interviews with myself. They would be about an hour long, and you would be paid \$50 for each one.
- Is this something you think you would be interested in? If you are still interested, we can go over the criteria for participation to see if you would qualify for the study. If not, thank-you so much for your time.

(At this point I would go over the screening questions which were a part of the original ethics application)

Participant Screening Guide

To be used over the telephone after a participant responds to the invitation to participate.

Thank-you for your interest in participating in this research study. I will need to ask you a few questions to ensure that you meet all of the criteria for the study.

First, are you a birth mother of a child with FASD?

Does your child have a diagnosis of FASD? (if not answered within the first question)

Are you currently parenting your child?

Are you over the age of 18?

This study will involve questions regarding your emotions and experiences around having a child with FASD. If you decide to participate, you and I will be meeting privately and I will be asking you some questions that may be very personal. Is this something that you think you would be ready for at this point in your life?

What type of supports do you have available to you if this research brings up some difficult emotions?

Thank-you, now that you have answered those questions we can set up a time to meet. When we meet, I will go over some more details about participation and how you can leave the study if you wish. Is there a time that would be good for you?

APPENDIX F

INTERVIEW GUIDELINE

The questions in this guideline are to be used as a guide in the semi-structured interviews to ensure quality data is collected. They are not intended to be used in the linear fashion presented here but rather to guide the conversation with participants and ensure all necessary areas are covered.

Introduction Questions:

To be used at the beginning of the first interview, to help in developing rapport.

Please tell me about yourself.

(This could include general background information, where the participant grew up, number of children, employment)

Overarching Question:

To be used at the beginning of the first and second interviews.

Please tell me about your experiences as a birth mother of a child with FASD since your pregnancy. I would like to know how FASD has impacted all areas of your life.

Prompts:

Prompts are to be used as necessary (primarily in the second interview), if each specific area is not addressed by the participant within the discussion of the overarching question.

- What was happening in your life during the time of your pregnancy?
- Could you tell me about the birth of your child?
 - What experiences did you have during labour and in the hospital with this child?
 - How did you relate to the nurses and doctors in the hospital during labour?
- Tell me about the process of diagnosis of your child.
 - How did you first consider a diagnosis of FASD for your child?
 - What were your emotions during the process of diagnosis?
 - What were your emotions after you found out the diagnosis?

- How old were you and your child during the time of diagnosis?
- How has your child's diagnosis impacted your relationship with your child?
- What has been your experience in dealing with your child's school and teachers?
- What has been your experience with the medical profession when seeking medical attention for your child?
- Can you give me an example of a time that you told someone about your child's diagnosis?
 - What were you feeling?
 - What reaction did they have?
- What are some of the best experiences you have had since the birth of this child?

Interview 3: Interpretive Interview

The purpose of the third interview is to offer the participants a chance to read and check their transcribed first two interviews, and also to check the initial themes which have emerged from the data for resonance with the participants. Participants will be sent the transcripts by mail a week before the third interview in order to read them for accuracy.

1. Participants will be first asked about their transcripts

Is there anything you would like changed?

Is there anything which I have gotten wrong in my transcription of your story?

Is there anything you would like omitted?

Is there anything in the story which may identify you which you would like omitted?

Is there anything you would like to add?

Would you sign the transcript release form to verify that you have checked it?

2. Participants will be asked to look over the tentative themes which have been generated from the data. It will be explained that the themes are generated from a variety of women's stories, and thus some of them will make sense to them, and others may be less like their personal experience.

How do you relate to these themes?

Do these themes seem to fit for you and your story?

Are there any themes which you do not identify with?

APPENDIX G
TRANSCRIPT RELEASE FORM

Experiences of Birth Mothers of Children with FASD

I, _____, have reviewed the transcripts of my personal interviews from this study. I have had the opportunity to add, change, and delete information from the transcripts. The transcript accurately reflects what I said in my interviews with Megan Wood. I authorize the release of this transcript to Megan Wood to be used in this research and as a part of a written report. I have received a copy of this Transcript Release Form for my records.

Participant

Date

Researcher

Date

APPENDIX H

ETHICS APPLICATION

1. a. Name of Researchers:

Laurie Hellsten (PhD), Department of Educational Psychology and Special Education, University of Saskatchewan.

Megan Wood, (MEd Candidate), School and Counselling Psychology, Department of Educational Psychology and Special Education.

1. b. Anticipated Start Date: June 15, 2009

Anticipated End Date: September 1, 2010

2. Title of Study: Experiences of Birth Mothers of Children with FASD

3. Abstract (100-250 words)

Fetal Alcohol Spectrum Disorder (FASD) refers to a group of diagnoses caused by prenatal exposure to alcohol. It is estimated that 9 in 1000 babies born in Canada are affected by FASD (Public Health Agency of Canada, 2003). The public discourse regarding substance abuse and pregnancy in Canada has been described as “blaming, judgemental and unsympathetic” (BC Centre of Excellence for Women's Health, 2007). All but one of the four FASD diagnoses requires confirmation of maternal drinking during pregnancy (Chudley et al., 2005). Therefore, blame on the biological mother is an inherent part of the diagnostic process. As of 2008, two qualitative studies have been published regarding birth mothers of children with FASD; both discuss guilt and stigma as common experiences (Salmon, 2008; Salmon, 2007).

I am interested in the roles that guilt, blame and stigma play in the lives of birth mothers of children with FASD. However, using a phenomenological framework, this study will be open to any experiences since the birth of the child. Phenomenology and a feminist framework will assist in gaining a greater understanding of the essence of the experience of being a birth mother of a child with FASD. Purposeful sampling will be used to recruit two to four birth mothers who have a child diagnosed with FASD, and who are parenting that child. Connections will be made with these women through the FASD Support Network of Saskatchewan. Data will be generated through semi-structured interviews, and analyzed using the methods outlined by van Manen (1990).

4. Funding

A funding application to the Social Sciences and Humanities Research Council of Canada has been submitted and has been sent forward by the University of Saskatchewan.

5. Expertise

This research is to be conducted with a population of women who may be considered vulnerable because of the stigma attached to being a birth mother of a child with FASD and the sensitive nature of the topic area. I worked with individuals with FASD and their families for two years as a Mentor-Advocate and Employment Support Coordinator with the FASD Support Network of Saskatchewan. Working in those positions I had the opportunity to learn from many birth mothers of children with FASD in the community and at several conferences throughout Canada. The FASD Support Network has a board comprised of mostly parents of children with FASD, so I also learned a great deal about the stresses of parenting a child with FASD through my working relationships with these individuals. I also worked with many birth mothers of children with FASD through my work at several group homes in Saskatoon, including Red Willow Centre and Bethany Home. In my current Master's in School and Counselling Psychology program I am also learning many interviewing and counselling skills that will assist me in discussing sensitive information in a respectful and considerate manner.

6. Conflict of Interest

The main potential for a conflict of interest in this research lies in my previous work experience with individuals with FASD in Saskatoon. I forged many close working relationships with their families, including birth mothers. The population of individuals with FASD in Saskatoon who are diagnosed and willing to discuss that diagnosis is not large. There is a potential that one or more of the birth mothers recruited for this study may be individuals whose children I worked with in the past. These mothers were thus not directly my clients in the past, but individuals whom I consulted with while working with their children. I will attempt to reduce the potential for coercion in participating in the research process by not contacting any of these individuals directly through the process of recruitment; possible participants will be contacted through the FASD Support Network of Saskatchewan. I will also carefully outline the voluntary nature of the study and procedures for withdrawal from participation within the consent form. The opportunity to withdraw and importance of consent will be repeated before each interview.

7. Participants

Participants for the study will be identified through sending out a recruitment letter to the mailing list of the FASD Support Network of Saskatchewan, which includes individuals with FASD, their family and friends and people who work with this population. The mailing list will not be seen by myself. The recruitment letter will explain the study and criteria for participation, and potential participants will be asked to contact myself. The proposed recruitment letter is attached as Appendix B.

This study involves in- person interviews with participants, thus their identities will be known to me. I will also ask for demographic information such as age, race, socio-economic status and number of children. That specific information is important to the context of societal stigma which is addressed in this study.

The criteria for participation in the study are as follows:

- a) Birth mother of a child or children diagnosed with FASD
- b) Living in Saskatoon and area
- c) Be 18 years of age or older
- d) Currently involved in the parenting of the child with FASD
- e) Be willing and able to tell their story

This specific population and inclusion criteria were chosen based on the phenomenon in question. The diagnosis is an important criterion to ensure the individuals involved in the study are associated with FASD. The study will focus only on birth mothers, excluding adoptive or foster parents or birth fathers. The rationale behind choosing that specific population relates directly to the research context of guilt and stigma in which birth mothers are blamed for their child's disability. The third inclusion criterion, that the mother must be involved in the parenting of the child with FASD, is also important in terms of the research question. I am interested in how a birth mother experiences parenting and the constant interaction with her child's disability within the context of guilt and stigma. The mothers must be willing and able to tell their story in order to ensure that further harm is not created in the telling of the sensitive information. Screening questions will be used over the phone to ensure the potential participants meet these criteria. The proposed guide for participant screening is attached as Appendix C.

8. Consent

The proposed written consent form is included as Appendix D. The consent forms will be read out loud to the participants with the researcher before any research activities are carried out. This will ensure that any participants with possible literacy issues understand the criteria of participation and their rights as participants. Signing the form will convey the participants' understanding of their rights and responsibilities and will be accepted as consent to participate in the study. The consent form will be signed by both the participant and the researcher before the first interview, and a copy will be provided to the participant. Verbal consent will be re-affirmed before the second and third interviews

All of the participants will be above the age of 18, and although there is a possibility that they may have had contact with the researcher in the past, they are not and never were in a dependent relationship with myself.

9. Methods/Procedures

Data will be generated through three semi-structured interviews with each participant. Interview times will vary, but will be approximately 1-2 hours in length. The interviews will be digitally recorded and transcribed. The semi-structured interview guide includes demographic questions, an overarching question and many prompts to be used if specific areas of the experience have not been addressed by the participant. The proposed interview guide is attached as Appendix F.

The first interview with each woman will consist of demographic questions, the overarching question and few prompts. The second interview with each woman will include detailed questions and prompts based on the story she told in the first interview. After the initial themes have been identified, I will return to each participant for a third interview in which I present their original transcripts, as well as the tentative themes. We will discuss the tentative themes to see if the women identify with the ideas which have been generated from the data. The use of three separate interviews will allow me to address more sensitive questions in the second interview, and also to engage in member checking and collaborative interpretation with the women in the third interview.

10. Storage of Data

The confidential data generated from this study will include digital recordings of the interviews, transcriptions, signed consent forms and any other documented communications with

participants. Names or identifying information of the participants will not be written on transcripts or digital files. During the study all data will be locked in a secure filing cabinet. Upon the completion of the study, Dr. Laurie Hellsten will be responsible for data storage at the University of Saskatchewan for five years.

11. Dissemination of Results

The data collected from this study will be primarily used for my thesis for the completion of a Master's of Education in School and Counselling Psychology. Secondly, I will submit a shortened version of the study for publication as a journal article or presentation at conferences. Thirdly, I will submit another version of the study as a publication for dissemination to members of the FASD Support Network of Saskatchewan. This will ensure that the results of this study are distributed to the individuals who participated in the study, as well as to individuals who work with birth mothers of children with FASD and could benefit from the information in the study.

12. Risk, Benefits, and Deception

The potential benefit of this study is an improved understanding of the experience of birth mothers of children with FASD since the birth of their child. This improved understanding may lead to further research, more informed programming with birth mothers of children with FASD, and perhaps a decrease in the stigma associated with the phenomenon.

The main potential risk involved in this study is related to the sensitive nature of the topic, and the emotions that may be involved for the women. I am interested in asking about the emotions that these mothers have experienced through the birth, diagnosis and parenthood of their child; there may be embarrassment, shame and guilt involved in aspects of their story. There is a potential for harm in these women having to tell their story and discuss these personal experiences and emotions. I will attempt to reduce this potential for harm by ensuring that the women are informed of the subjects to be discussed at the outset of the research and that the women are informed of their right to withdraw before each interview. I will inform the women of the possibility to stop the interview at any time, to not answer any questions or to take a "time out" from the interview if needed. I will also providing a list of potential referrals for support at the outset of each interview. This list will include free counselling and support services available to the women, such as the abuse groups with Family Services Saskatoon and the Adult Mental Health intake line. The proposed list of services to be provided to participants is attached as Appendix E. As well my supervisor, Dr. Laurie Hellsten, and my committee member, Registered

Doctoral Psychologist Dr. Stephanie Martin, will be available for consultation in the event of any participant expressing distress during an interview.

13. Confidentiality

Loss of privacy or confidentiality is possible in that Saskatchewan is a relatively small community, and birth mothers of children with FASD are a specific population. There is a possibility that individuals may be identified through their stories. To reduce the likelihood of the identification of participants, names and demographic information will not be included in the final representation of the data, and no stories which contain identifying information will be included in the reports. The women will also be able to look through their transcripts in the third interview, and at that time they will be asked if there are any pieces of their story which they would like removed from the transcript because of the possibility of their identification. Tapes and transcripts will be identified by the researcher through codes; no names will be attached to the files.

14. Data/Transcript Release

As mentioned, above, each woman will have the opportunity to review the transcripts from her interviews and remove any details which may identify her or change any information. Each participant will be asked to sign a transcript release form, which is attached as Appendix G.

15. Debriefing and feedback

The women will be verbally debriefed at the end of each interview. Those interested in obtaining results from the study will be invited to contact myself or Dr. Laurie Hellsten. The participants will receive a copy of the shortened version of the study which will be provided for distribution through the FASD Support Network of Saskatchewan.

16. Required Signatures

Megan Wood, MEd Candidate

Dr. Laurie Hellsten, Supervisor, Department of Educational Psychology and Special Education

Dr. David Mykota, Department Head, Educational Psychology and Special Education

17. Required Contact Information

Megan Wood: mew345@mail.usask.ca

384-1063/ 717-0936

243 O'Regan Cres Saskatoon, SK S7L 6N4

Laurie Hellsten: laurie.hellsten@usask.ca

966-7723

Office: ED 3110, 28 Campus Dr., Saskatoon SK S7N 0X1

David Mykota: david.mykota@usask.ca

966-5258

Office: ED 3102, 28 Campus Dr., Saskatoon SK S7N 0X1

APPENDIX I

ORIGINAL ETHICS APPROVAL

UNIVERSITY OF SASKATCHEWAN



UNIVERSITY OF
SASKATCHEWAN

Behavioural Research Ethics Board (beh-REB)

Certificate of Approval

PRINCIPAL INVESTIGATOR
David Smith, University of Saskatchewan

DEPARTMENT
Department of Psychology and Neuroscience

REVIEW
2013-12-17

INSTITUTIONAL REVIEW BOARD (IRB) CONDUCTED BY
University of Saskatchewan

STUDY RESEARCHERS
Allyson Wood

SPONSOR
SQUAT SUBJECTS AND LEAVAN, THE RESEARCH COUNCIL OF CANADA (SURREY)

TITLE
Experiment 2 of our 2013-2014 research with RABD

ORIGINAL REVIEW DATE
06-12-2009

APPROVAL ON
06-12-2009

APPROVAL BY
Ethics Approval
Committee Protocol

EXPIRY DATE
06-12-2011

Full Board Meeting ☒

Date of Full Board Meeting 06-12-2009

Delegated Review ☐

DECLARATION

The University of Saskatchewan Behavioural Research Ethics Board has reviewed, and approved, the research project. The principal investigator is responsible for ensuring that the research project is carried out according to the conditions outlined in the original protocol submitted for ethics review. This Certificate of Approval is valid for the duration of the project and any changes to the project must be reported to the Behavioural Research Ethics Board for review and approval.

Any significant changes to your project, method, or participant and recruitment procedures should be reported to the Behavioural Research Ethics Board for review and approval.

ONGOING REVIEW REQUIREMENTS

An annual review of your project must be submitted to the Behavioural Research Ethics Board for review and approval. A written report of the current status of the project, including a description of the project, the study, the results, and the study completion. Please refer to the following website for further information: <http://www.beh-reb.ca>

David Smith, Principal Investigator

University of Saskatchewan
Behavioural Research Ethics Board

For more information, please contact:

Research Ethics Office
University of Saskatchewan
Saskatoon, Saskatchewan S0N 0W0
Saskatchewan, Canada

APPENDIX J

ETHICS REVISION #1 APPROVAL



UNIVERSITY OF
SASKATCHEWAN

Behavioural Research Ethics Board (Par. RLEB)

Certificate of Approval Study Amendment

PRINCIPAL INVESTIGATOR
Laurie Ann Hoffmeyer

DEPARTMENT
Educational Psychology and Special Education

File #
06-125

INSTITUTIONS WHERE RESEARCH WILL BE CARRIED OUT
University of Saskatchewan

STUDENT AND RESEARCHER(s)
Megan Wood

SPONSORING AGENCIES
SOCIAL SCIENCES AND HUMANITIES RESEARCH COUNCIL OF CANADA (SSHRC)

TITLE
Experiences of Birth Mothers of Children with ASD

APPROVAL OF
Revised Recruitment Protocol (Option #1)
-Recruitment Poster
-Board recruitment region (Saskatchewan)
-Addition of Snowball Sampling
-Resending recruitment posters
-Recruiting from the FASD Network Panel Retreat
-Change in interview settings

APPROVED ON
29 Oct 2009

CURRENT EXPIRY DATE
29-Jun-2010

Full Board Meeting ☐

Date of Full Board Meeting

Delegated Review ☒

CERTIFICATION

The University of Saskatchewan Behavioural Research Ethics Board has reviewed the above named research project. The proposal was found to be acceptable on ethical grounds. The principal investigator has the responsibility for any other administrative or regulatory approvals that may pertain to this research project, and for ensuring that the authorized research is carried out according to the conditions outlined in the original protocol submitted for ethics review. This Certificate of Approval is valid for the above time period provided there is no change in experimental protocol or consent documents.

Any significant changes to your proposed method, or your consent and recruitment procedures should be reported to the Chair for Research Ethics Board consideration in advance of its implementation.

ONGOING REVIEW REQUIREMENTS

In order to receive annual renewal, a status report must be submitted to the AHB Chair for Board re-consideration within one month of the current expiry date each year the study continues, and upon study completion. Please refer to the following website for further instructions: <http://www.uhsask.ca/research/ethics/ethics>

Edie Riebel, Chair
University of Saskatchewan
Behavioural Research Ethics Board

Revised version of manuscript

Research Ethics Office
University of Saskatchewan
Box 4407 STN University S4S 0A2
Saskatoon, SK S4N 0A8

APPENDIX K

ETHICS REVISION #2 APPROVAL



**UNIVERSITY OF
SASKATCHEWAN**

Behavioural Research Ethics Board (Beh-REB)

Certificate of Approval Study Amendment

PRINCIPAL INVESTIGATOR Laurie Ann Hellsten-Hazewy	DEPARTMENT Education, Psychology and Special Education	REG. 00-129
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INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT
University of Saskatchewan

STUDENT RESEARCHER(S)
Megan Brook

SPONSORING AGENCIES
SOCIAL SCIENCES AND HUMANITIES RESEARCH COUNCIL OF CANADA (SSHRC)

TITLE
Experiences of Birth Mothers of Children with FASD

APPROVAL OF
Revised recruitment protocol
+ Snowball sampling protocol and script.

APPROVED ON
03-Dec-2009

CURRENT EXPIRY DATE
29-Jan-2010

Full Board Meeting ☐

Date of Full Board Meeting:

Delegated Review ☒

CERTIFICATION

The University of Saskatchewan Behavioural Research Ethics Board has reviewed the above named research project. The proposal was found to be acceptable on ethical grounds. The principal investigator has the responsibility for any other administrative or regulatory approvals that may pertain to this research project, and for ensuring that the authorized research is carried out according to the conditions outlined in the original protocol submitted for ethics review. This Certificate of Approval is valid for the above time period provided there is no change in experimental protocol or ethical process or documents.

Any significant changes to your proposed method, or your consent and recruitment procedures should be reported to the Chair for Research Ethics Board consideration in advance of its implementation.

ONGOING REVIEW REQUIREMENTS

In order to receive annual renewal, a status report must be submitted to the R.E.B. Chair for Board consideration within one month of the current expiry date each year the study remains open, and upon study completion. Please refer to the following website for further instructions: http://www.usask.ca/ethics/research_ethics/index.html

John Bigby, Chair
University of Saskatchewan
Behavioural Research Ethics Board

Printer: Sandra Gaudet-Bouillon

Research Ethics Office
University of Saskatchewan
Box 5500 RPO University 1029-11th Avenue N.W. 10
Saskatoon S4N 0A8

APPENDIX L
INFORMED CONSENT FORM

You have been invited to participate in the **voluntary** research project entitled “Experiences of Birth Mothers of Children with FASD.” Thank-you for your interest in participating in this study. Please read this form carefully and ask any questions you may have.

Researchers: Laurie Hellsten, PhD. Department of Educational Psychology and
Special Education, University of Saskatchewan.
Megan Wood, MEd Candidate, Department of Educational Psychology and
Special Education, University of Saskatchewan.

Participation will involve the following:

- a) Two separate 1-2 hour interviews in a private setting regarding your experiences, emotions and ideas about being a birth mother of a child with FASD.
- b) A third 1-2 hour long interview in which you and the researcher discuss the common experiences of birth mothers of children with FASD.
- c) Reviewing the interview transcripts to ensure your experiences were correctly recorded and interpreted.

In total, participation will require approximately 4-6 hours of your time over several months. I will ask you to share your story and emotions around being a birth mother of a child with FASD. I will audiotape these interviews and transcribe (type out) the taped conversations. Quotations of some of your own words may be used in the report for this study, but your name and other information that may identify you will be kept private. The information you share will be used to inform my thesis and possibly several other written documents, such as a publication at the FASD Support Network of Saskatchewan, or an article in a journal.

Potential Risks:

I will ask you to share personal information about your feelings and experiences as a birth mother of a child with FASD. I may ask about things like your child’s diagnosis, the birth of your child or your experiences parenting your child. These topics may bring up difficult

emotions for you. If at any time you wish to not answer any of my questions or end a discussion you may do so. A list of possible sources of support and counselling is provided with this form in case you experience any negative feelings throughout the participation in this study.

Potential Benefits:

Participation in this research study will provide you with a safe and confidential place in which you can talk about your experiences as a birth mother with FASD. You may find it beneficial to talk about your experiences and share your emotions in this way. By sharing your story, you may possibly help others have a greater understanding of the experiences of birth mothers of children with FASD.

Confidentiality:

Several strategies will be used to protect your confidentiality in this study. Your name and all other information which may identify you (such as your address or your child's name) will be known only to the researcher. Pseudonyms (fake names) will be used in the report so that you are not identified. This consent form which has your name on it will be stored separately from the transcripts and audio recordings, so that your name cannot be attached to your story. You will have the opportunity to read the transcripts from your interviews and at that time you may remove or change any information which you think may identify you to others. The transcripts and audio recordings will be identified by codes which are known only to the researcher, and will be stored in a locked cabinet. Following the completion of the study, the information you shared will be stored in a locked cabinet by Dr. Laurie Hellsten, at the University of Saskatchewan, for five years.

Right to Withdraw:

If at any time during this study you feel that you no longer want to participate, you may leave the study with no penalty. Please inform me if you wish to leave the study, and you can do so immediately. If there are any questions you do not wish to answer you may refuse to answer at any time. You may request that the tape recorder be turned off at any time. If you choose to leave the study, all information that may have been collected from you will be destroyed.

Other Information:

- I will inform you of any changes or new information that may impact your decision to participate.
- This research has been reviewed and approved by the University of Saskatchewan's Behavioural Research Ethics Board on (insert date).
- If you have any questions at any time throughout the study, please contact myself at 717-0936/ mew345@mail.usask.ca or Dr. Laurie Hellsten at 966-7723

Consent:

I have read this consent form, and understand my right to choose to participate in this study. I understand the above information and have been given an opportunity to ask questions. By signing this consent form I agree to participate in the study as described, unless I choose to withdraw at any time. A copy of this consent form has been given to me for my records.

Signature of Participant

Date

Signature of Researcher

Date

APPENDIX M POSSIBLE REFERRAL SOURCES SASKATOON

If you feel that you would benefit from speaking to a counsellor after sharing difficult parts of your story, please consider contacting one of the following agencies:

- Family Services Saskatoon
244-0127
102- 506 - 25th Street East, Saskatoon
 - Offers individual, family and group counselling
 - Fees are on a sliding scale based on your income. Also accept payment from employment insurance programs
- Catholic Family Services
244-7773
200 506 25th St E, Saskatoon
 - Offers individual, family and group counselling.
 - Fees are on a sliding scale based on your income. Also accept payment from employment insurance programs
- Saskatoon Adult Mental Health Services
Intake Line: 655-7950
715 Queen Street, Saskatoon
 - Adult Community Mental Health Services program provides mental health services to adults, families, groups and communities
 - Services are free with your Saskatchewan Health card
- Westside Community Clinic
664-4310
631 20th St W., Saskatoon
 - Group programs, health care services and drop-in counselling services
- Community Addictions Services
655-4100
156-122 3rd Ave N. Saskatoon
 - Services for substance abusing individuals and their families

If you would like more information about FASD, or would like to speak to another parent of a child with FASD, please contact the FASD Support Network of Saskatchewan, 975-0884/fasdnetwork@sasktel.net, website: <http://www.skfasnetwork.ca>.